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Health Promotion among Young Adult African American Men with Invisible Disability

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Health Promotion among Young Adult African American Men with Invisible Disability

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Dedication

I lovingly dedicate this dissertation to the African American men in my life who have loved, supported, encouraged, guided, provided for, and sacrificed for me even in the midst of their own struggles. Lawson, Bruce, Tyler, Brian, Uncle Bobby, and Ecleamus, Sr., I love and cherish each of you on this day and always. Thank you for helping me find balance.

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Consider it pure joy, my brothers and sisters, whenever you face trials of many kinds, because you know that the testing of your faith produces perseverance. Let perseverance finish its work so that you may be mature and complete, not lacking anything.

James 1: 2-4

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Health Promotion among Young Adult African American Men with Invisible Disability

Tiffany Nicole Ricks, PhD

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Supervisor: Tracie C. Harrison

The purpose of this study was to explore the lived experience of health promotion for a group of young adult African American men with invisible disabilities. This hermeneutic phenomenological study used a non-experimental, descriptive design. The purposive sample consisted of 11 young adult, English-speaking, non-institutionalized, African American men with invisible disability between the ages of 25 and 39 years of age living in the Central Texas metropolitan area. This study's research questions were answered using audio-taped, one-on-one qualitative interviews along with detailed fieldnotes. Participants were interviewed twice at a mutually decided upon location to ensure the privacy and comfort of participants. For these young men, an essential component of health promotion involved the reestablishment and reorganization of their bodies in the world while adjusting to living with disability. For them, the essential structure of health promotion was comprised of the following themes: Reconciling Perspectives of the Self, Embracing the Current Body, and Reorienting the Body in the World. Their lived experience of health promotion was reflected in the following themes: Risking the Body to Preserve the Self, Accepting the Evolving Body, and Seeking the Body's Redemption. For this group of young adult African American men, their health promotion experience required risking the body, putting the needs of the self before the needs of the body, and then accepting and valuing the resulting condition of the body.

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Chapter 1: Introduction

> I think functioning should be the main priority. Being able to fully function in society is way better than money. I can have all the money in the world but it ain't no good if I can't get up and spend it. (Participant 2)

Imagine suffering from chronic nerve and back pain for the last six years after having been shot four times while walking down a street in your neighborhood. Even though you consider yourself both mentally and physically disabled, imagine being thrice denied the disability benefits you need to provide for yourself and your family. How would your outlook on life change if you suddenly acquired an invisible disability that left you in agonizing pain on a daily basis and made it nearly impossible for you to jog around the block or bend over and tie your own shoes? Imagine being an accomplished athlete one day, and walking with a limp the next, unable to do a single push-up. Now imagine not telling your track coach about the excruciating back pain you experience when you run because you do not want to lose the track scholarship you consider your ticket out of poverty. The investigator understands that simply imagining oneself in a certain situation does not give adequate justice to what an individual sees, feels, hears, and believes while in the midst of an experience. Due to the limitations of the imagination, the investigator had to rely on hermeneutic phenomenology to gain insight into the lived experience of health promotion for a group of young adult African American men with invisible disability. This exploration of their health promotion experience begins with an introduction to the factors that influence their health, health habits, perceptions, and experiences.

The need for health care providers to explore and understand the health promotion experience of young adult African American men with invisible disability becomes evident upon the examination of factors that contribute to the propensity of health

disparities among this population. Two of the greatest risk factors for poor health outcomes are race and disability. Among all racial groups, African Americans experience the highest number of poor health indicators. Specifically, African American men have the highest incidence and mortality rates for all cancers including prostate, lung, and colorectal (The Office of Minority Health, 2007). Furthermore, African American men experience more than eight times the AIDS rate and are more than nine times as likely to die from HIV/AIDS when compared with non-Hispanic white men (The Office of Minority Health). As a result of having high levels of life threatening illness, African American men report a shorter life expectancy than both African American women and non-Hispanic white men (DeCuir, Wicks, & Rice, 2009). In the time period preceding death, many African American men live with the effects of disabling functional limitations.

Disability is a major public health issue for African American men. Almost 20% of African American men report living with disability-the highest rate of disability among men when compared to White, Asian, and Hispanic men (Brault, 2008). Living with a disability adds a second dimension of risk to the possibility of having poor health outcomes for African American men. This is because people with disabilities are more likely than people without disabilities to engage in health damaging behaviors, such as smoking and inactivity, and they have a notoriously low level of access to quality health care (Centers for Disease Control [CDC], 2010). Despite being one of the most at-risk groups in the nation, there is a dearth of knowledge regarding ways to help African American men with disabilities promote their health.

When compared to persons with more outwardly obvious disabilities, the challenges and health related needs of individuals with invisible disabilities are often ignored in research (Keigher & Jurkowski, 2001). Invisible disabilities have been found to be associated with feelings of shame, stigma, and frustration (Cortés, Hollis, Amick, &

Katz, 2002). Invisible disabilities are disabilities that are not observable and cannot be substantiated by others (Matthews & Harrington, 2000). In other words, the disability is not obvious to the onlooker. Invisible disabilities may include chronic pain (Lillrank, 2003), fatigue, or muscle weakness (Stone, 2005). According to Stone (2005), invisible disabilities may generate more issues for an individual than overtly visible disabilities due to their inability to "fit" neatly into either a disabled or non-disabled category. Persons with invisible disabilities are likely to exist in a state of ambiguity regarding their collective identity. Stone asserts that:

> For those who do not appear to be disabled, we tend to judge them according to conventional standards about what constitutes acceptable behavior. The hegemony of dualistic thinking means that there is the assumption of an unproblematic divide between disabled/abled. Coupled with the belief that decisions about who belongs in which category can be determined with empirical evidence, there is no room for recognizing that those who appear to be abled may nevertheless have unseen difficulties. (p. 294).

The belief that the paradoxical existence and identity that may be experienced by young African American men with invisible disability is likely to shape their perceptions of health and illness, spurred this researcher's interest in exploring their associated meanings of health related choices and behaviors. How African American men are best able to survive and thrive after experiencing disability, specifically invisible disability, has not been explored. It was the objective of this researcher to explore ways in which African American men may best promote their health while aging with invisible disability.

Young African American men with disabilities hold the potential to age into a long and healthy life, as people with early onset disabilities have begun to live longer than ever before in history (Campbell, Sheets & Strong, 1999). In order to accomplish this, their health care providers need to be knowledgeable of the health promotion strategies that might give these young men the keys to healthy aging. Several studies

have examined the plethora of health problems that exist among African American men with disabilities in the later stages of the life course (Chumbler, Hartmann, Cody, & Beck, 2001; Kominski et al., 2002; Liao, McGee, Cao, & Cooper, 1999; Miller, Wolinsky, Malmstrom, Andresen, & Miller, 2005); however, there is a scarcity of literature exploring the underlying factors and experiences at earlier stages in the life course that contribute to the development of health problems over time. Further, the literature reveals a paucity of research that provides practitioners with insight into the health promotion experience of young African American men with disabilities. This insight may assist healthcare providers in understanding the health needs of young African American men with disabilities as well as facilitate a patient-provider relationship based on a mutual understanding of experience. The common understanding of experience may lead to reciprocal respect and trust, which Plowden and associates (2006) identified as being integral to African American men's participation in health promoting interventions. Health promotion interventions for African American men with disabilities cannot be developed without their voice.

To capture the unique voice of the young adult African American men who participated in this study, a qualitative design was used. Specifically, hermeneutic phenomenology (Cohen, Kahn & Steeves, 2000) was employed to guide the study of the meaning of health promotion among African American men with permanent mobility impairment. The men were interviewed twice and demographic data was collected. This study explored the essential structure and ascribed meaning of health promotion for these men to inform future health promoting interventions.

Results of the study will be used for the design of health promotion interventions for young African American men with disabilities. Instead of designing health promotion interventions and treatment modalities for the general population and then applying them to persons with disabilities, Harrison (2006) suggested that future research focus on the

creation of health promotion interventions specifically tailored for persons with disabilities. No studies were found to date that specifically explored the lived experience of health promotion for young adult African American men with a disability, specifically invisible disability. This study will help fill that gap in the literature.

STUDY PURPOSE

The purpose of this study was to explore the lived experience of health promotion for young adult African American men with invisible disability. Results of this study will contribute to the development of health promotion interventions for African American men between the ages of 25 to 39 years of age with invisible disability.

RESEARCH QUESTIONS

1. What is the essential structure of health promotion from the perspective of young adult African American men with invisible disability?
2. What is the lived experience of health promotion for young adult African American men with invisible disability?

BACKGROUND AND SIGNIFICANCE

There are an estimated 54 million people living with disability in the United States (Brault, 2008) and of those, 15.3 million are between the ages of 18 and 44 (CDC, 2008). In addition, 19.3% of African American men report living with a disability-the highest rate of disability compared to White, Asian, and Hispanic men (U.S. Census Bureau, 2008). It has been documented that people aging with a disability are at risk for poor health outcomes (Harrison & Stuifbergen, 2001; Dejong et al., 2002), so one can suggest that young African American men with disabilities are at risk for poor health outcomes as they age. Further, documentation has highlighted the poor health outcomes that African American men experience as they age (Williams, 2003; Mendes de Leon,

Barnes, Bienias, Skarupski, & Evans, 2005; Gwede & McDermott, 2006). Hence, it is expected that African American men aging with early onset disability would be at increasing risk for poor health related outcomes over time. If practitioners are to curtail the problems that may arise over time, further research to understand the health promotion needs of young African American men with disabilities is currently needed to decrease the development of future health problems.

The health related needs of individuals with invisible disabilities have been ignored in recent research (Keigher & Jurkowski, 2001). Living with invisible disabilities often leads to feelings of shame, stigma, and frustration (Cortés, Hollis, Amick, & Katz, 2002). Invisible disabilities are impairments or disabilities that are not observable and cannot be substantiated by others (Matthews & Harrington, 2000) and may generate more issues for an individual than overtly visible disabilities due to their inability to "fit" neatly into either a disabled or non-disabled category (Stone, 2005). Persons with invisible disabilities are likely to exist in a state of ambiguity regarding their collective identity.

The belief that the paradoxical existence and identity that may be experienced by young African American men with invisible disability is likely to shape their perceptions of health and illness, spurred this researcher's interest in exploring their associated meanings of health related choices and behaviors. How African American men are best able to survive after the onset of a disability, specifically invisible disability, has not been explored. It was the objective of this researcher to explore ways in which African American men may best promote their health while aging with invisible disability.

A thorough understanding of the contextualized experience of health promotion is needed in order to design a more personalized and meaningful approach to health promotion. For the purpose of this study, health promotion was defined as “behavior motivated by the desire to increase well-being and actualize human health potential” (Pender, Murdaugh, and Parsons, 2006, p. 7). A uniform approach to health promotion

has become outdated and for persons with disabilities, current health promotion interventions require refining and tailoring in order to be efficient and effective (Stuifbergen, 2006; Timmerman, 2007). This study explored what young adult African American men with invisible disabilities do to improve their health as well as the motivations behind those behaviors.

Young adults follow various trajectories to adulthood. Each path chosen has implications for adult health outcomes (Park, Mulye, Adams, Brindis, & Irwin, 2006). Pender and colleagues (2006) assert that "the purest form of motivation for health promotion exists in childhood through young adulthood when energy, vitality, and vigor are important to attain but the threat of chronic illness seems remote" (p. 7). How is this motivation for health promotion altered in the context of a developmental age and permanent disability? Some researchers assert that the overall health status of young adults can be improved through effective health promotion interventions and increasing access to quality medical care (Park et al.). The designing of effective, relevant preventative health programs for young adult African American men with invisible disability begins with a thorough understanding of their lived experience of health promotion.

It is imperative that health care providers understand how young adult African American men with invisible disabilities perceive and experience their bodies as it provides awareness into the personal philosophies, rationales and decision making processes involved in caring for their health. The significance of understanding the experience and perceived meaning of health promotion is that it may better equip health care providers with the tools necessary to more effectively meet the health needs of the persons they care for, thereby improving long-term health outcomes.

SENSITIZING FRAMEWORK

The concept of health-within-illness (Lindsey, 1996; Moch, 1998) and the philosophical framework of hermeneutic phenomenology provided the means to explore health promotion during the developmental period known as young adulthood in African American men with mobility impairment. According to Merleau-Ponty (1945), “The body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment” (p. 94). The life experiences of young African American men with invisible disability are unique and will be different from any other group of men with disabilities (Devlieger, Albrecht, & Hertz (2007); therefore it stands to reason that their health promotion experiences and subsequent health needs will be different as well. According to Ostrander (2008), "an African American man with a disability has specific experiences that are racialized, gendered and disabled. These experiences are particular to his combination of identity categories and contribute to individuals’ expressions of their race, gender and disability" (p. 587).

The understanding of contextualized health promotion for African American men with invisible disability provides sensitivity to and appreciation of the effects that race, gender, and environment may have on the experience. It is imperative that health care providers gain understanding of the lived experience of health promotion in order to better understand how to best care for and promote the health of young adult African American men with invisible disabilities. This study provided insight into the health promotion experience of young adult African American men with invisible disability in the context of their personal and social environments.

A study exploring the health promotion experience of persons with disabilities must begin with the idea that health promotion in disability is feasible. The belief that health promotion and disability can co-exist is supported by the concept of health-within-illness. Krahn and associates (2006) assert that an “appreciation of the capacity for people

of all ages to be both disabled and healthy is growing" (p. 18). The concept of health-within-illness is viewed as an "opportunity" (Moch, 1998, p. 305) to improve one's sense of well-being and quality of life in the context of a disability (Lindsey, 1996). Health-within-illness becomes possible as we embrace the notion that the body's experiences of health and illness are interconnected and one experience cannot exist without the other (Lindsey). Being that the totality of experiences (i.e. health and illness) depends on each phenomenon being acknowledged and appreciated, and the body being the focal point of all perception (Husserl, 1999), the concept of health-within-illness becomes plausible as a framework for exploring the meaning of the health promotion experience of young adult African American men with invisible disability.

The ability to authentically capture life experiences is only possible when researchers use philosophical frameworks designed to do so. Phenomenology (Husserl, 1999), the study of life experiences, is appropriate for encapsulating individual life experiences. For Husserl, phenomenology involved getting at the essence of an experience regardless of the context in which the experience took place. Husserl emphasized the totality of an experience and believed that the experience of a phenomenon begins with the body, which is considered the starting point for consciously interpreting and understanding one's environment. Husserl asserted that what is perceived or actual, begins with a "zero point of orientation" (Husserl, p. 164) created by one's own body. Like Husserl, Merleau-Ponty (1945) believed "the body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment" (p. 94). Using phenomenology to explore the lived experience of health promotion can be a valuable avenue for discovering the *personal* meaning of caring for one's health in the context of disability. It is imperative that health care providers understand how young adult African American men with invisible disability perceive and experience their bodies as this understanding can provide awareness into the

personal philosophies, rationales and decision making processes involved in promoting their health.

As noted, phenomenology is primarily concerned with describing the essence of an experience; hermeneutic phenomenology expands this exploration of a phenomenon by interpretation of participant motivations and experiences while appreciating the context in which they occur (van Manen, 1990). Hermeneutic phenomenology uses both an interpretive and descriptive foundation (Heiddeger, 1962; Husserl, 1999; Laverty, 2003) from which to focus on understanding the meaning and impact of an experience. According to Laverty, "hermeneutic research is interpretive and concentrated on historical meanings of experience and their developmental and cumulative effects on individual and social levels" (p. 15). Using an interpretive paradigm challenges researchers to uncover the personal meanings assigned to an experience by participants (Crotty, 2003). Hermeneutic phenomenology was used as the sensitizing framework that informed the methodological decisions made in the conduct of this study.

Using a hermeneutic phenomenological, interpretivist framework and methodology, the developmental period known as young adulthood provided the context for interpreting the results of this study. This developmental time period is characterized by more stable views of health promotion than are earlier developmental time periods. For instance, emerging adulthood, consisting of ages 18-25, is viewed as a time “when little about the future has been decided for certain” (Arnett, 2000, p. 469). It is characterized as a period of experimentation and evolving societal and personal expectations for roles and identity formation (Arnett, 2000, 2003). In contrast, young adulthood extends through the thirties and is a period of greater stability than that of emerging adulthood. Heavily dependent on their cultural and social environment, the explorative and risk-taking behaviors that characterize the emerging adulthood period commonly continue until persons are almost 30 years of age. It is during this transitional

period to young adulthood, beginning in the mid to late twenties, in which long-term beliefs, “enduring decisions” (2000, p. 473), and self-identities become normalized for the individual. The adoption of sustained health promotion behaviors can be considered one such “enduring decision.” In addition, how individuals routinely perceive their bodies in relation to their perceptions of self worth and potential is likely to have implications for their health promoting practices. Young adulthood may be considered an appropriate developmental context for studying health promotion as it relates to the long-term health outcomes for African American men.

DEFINITIONS

For the purposes of this study, disability, functional limitation, and impairment are defined by Verbrugge and Jette (1994), who in their work regarding the disablement process, expanded the disability framework created by Nagi (1991).

- **African American** is defined by Grieco and Cassidy (2001) as any United States citizen with Black African ancestry. This study will only include persons born in the United States who self-identify as African American.
- **Aging with Disability:** Individuals with early onset disability, or disability that occurs early on in life, are said to be "aging with disability" (Verbrugge & Yang, 2002).
- **Disability** is defined as the inability to perform a socially constructed role such as employee or socialite, secondary to a functional limitation (Verbrugge & Jette, 1994). According to Verbrugge and Jette, the trajectory from pathology to disability is shaped by numerous categories of risk factors, interventions, and "exacerbators" (p. 1) that have the potential to either slow or quicken one’s progression to disability. The development and level of impairment, functional limitation, and disability attained, is determined by the presence or absence of risk

factors and "exacerbators" (p.1), as well as the effectiveness of health related interventions.

- **Emerging adult/adulthood** defines the developmental period from ages 18-25 (Arnett 2000).
- **Ethnicity** is the common worldview, language, and behaviors associated with a cultural heritage (McMahon & Watts, 2002).
- **Functional limitation** is defined as the inability to perform a physical act such as standing or walking (Verbrugge & Jette, 1994).
- **Health disparity:** "*Health disparities* are differences in health outcomes between groups that reflect social inequalities" (Frieden, p. 1, 2011).
- **Health promotion** is defined as "behavior motivated by the desire to increase well-being and actualize human health potential" (Pender, Murdaugh, and Parsons, 2006, p. 7).
- **Impairment** refers to "dysfunctions and significant structural abnormalities in specific body systems" (Verbrugge & Jette, 1994, p. 3).
- **Invisible disability** refers to impairments that are not observable and cannot be substantiated by others (Stone, 2005); Literature regarding the concept "invisible disability" uses the term disability in the same way that this study uses the term impairment; therefore, for the purposes of this study, the term invisible disability will be used to indicate invisible *impairment*.
- **Mobility impairment:** "refers to the inability of a person to use one or more of his/her extremities, or a lack of strength to walk, grasp, or lift objects" ("Mobility Impairments, 2012).
- **Race** is a "group that is socially defined as having certain biological characteristics that set them apart from other groups, often in invidious ways" (Pincus & Ehrlich, 1999, p. 12).

- **Young adult/adulthood** is defined as the developmental period from approximately ages 26-39 (Arnett, 2000)**.**

ASSUMPTIONS

The following assumptions are associated with this study:

1. According to Merleau-Ponty (1962), our body accompanies everything that we do and is inherently involved in every aspect of our perspectives, ideas, and imaginations.
2. African American young men with functional limitations have engaged and/or are currently engaging in some aspect of health promotion.
3. Study participants have reflected on their unique life experiences in order to apply context and personal meaning to their current life situation.
4. Study participants wanted to share their experiences with the investigator.
5. The investigator's experiences, background, values, and ideas influenced and enhanced the interpretation of the data gathered.

BRACKETING BIAS

From a methodological perspective, phenomenology and hermeneutic phenomenology are both interested in understanding human experiences, but each has a different data analysis process and objective. For example, in his viewpoint, Husserl (1999) would assert that the researcher must "parenthesize" or bracket his/her own personal perspectives and assumptions of experiences during the analysis process. Husserl believed that the true essence of a phenomenon is able to emerge only after the researcher's empirical knowledge has been removed from data analysis. Heidegger (1962) claimed that this attempt to bracket is an exercise in futility being that our bodies are never separate from our minds nor can our minds interpret independently of our past experiences. With Heidegger, hermeneutic phenomenology moved from Husserl's focus

on uncovering a phenomenon to 'Dasein', that can be interpreted to mean the idea of being human or existing in the world (Laverty, 2003, p. 7). In essence, Heidegger believed that our lives unfold in a constant state of interpretation based on our own personal biases and perspectives. This interpretation is considered a part of our everyday lives; it is considered a part of our core being; therefore, it would be impossible to divorce our interpretations from this state of existence.

In hermeneutic phenomenology, the researcher is expected to consider and use his/her biases and experiences in the interpretive process (Laverty, 2003). Throughout this study, the researcher expected that her own personal history, perspectives, assumptions and past experiences would influence data collection and analysis. Although the researcher using hermeneutic phenomenology cannot completely disconnect their interpretations from their personal histories, reasonable, authentic attempts can be made to minimize biases associated with those histories. The researcher diligently and continually identified and recognized her personal history and how it might have impacted each phase of this study. Kahn (2000) suggests that researchers undergo continual "critical reflection" as a framework for minimizing potential bias during the research process (p. 86). Critical reflection is ongoing, but begins with the researcher being open and honest about their personal preconceptions, assumptions, and beliefs and how they can potentially influence the research process (Kahn).

In order to authentically capture the lived experience of health promotion for young adult African American men with disability, the investigator engaged in critical reflection throughout all stages of this study. Being an African American woman and nurse without a disability, the investigator was already aware that she had assumptions regarding the health promotion experience of young adult African American men with disabilities that are grounded in her own limited interactions with this population. In addition, as a health care provider, the researcher was aware that she had pre-conceived

notions of what health promoting behaviors and activities look like based on her past experiences with adult populations.

CHAPTER SUMMARY

In summary, although the potential for healthy aging is plausible, there is a paucity of literature regarding the health promotion experiences and needs of young adult African American men with disabilities and specifically invisible disabilities. Using health within illness (Lindsey, 1996; Moch, 1998), from hermeneutic and phenomenological perspective, as a sensitizing framework, and hermeneutic phenomenology as a guiding methodology, this qualitative study provided insight into the lived experience of health promotion for young adult African American men with invisible disability. By understanding the meaning and lived experience of health promotion for young adult African American men with invisible disability, health care providers may become better equipped to design effective health promotion interventions aimed at this population.

Chapter 2: Review of the Literature

This chapter will discuss several areas of literature pertinent to understanding the impetus to study the health promotion experience of young adult African American men with invisible disability. The literature review begins with an overview of how disability is defined and associated implications. The next section discusses invisible disability followed by a section exploring the relationships that exist between disability and health. The next section examines disability among young adults in the United States. Next, the concept of health-within-illness and its use in the context of disability is discussed. The sixth and seventh sections are an overview of the current state of African American men's health along with a discussion of masculinity and the health of African American men. These sections include an exploration of the social determinants of health for African American men and health outcomes of African American men with disabilities in order to illuminate health disparities specific to this population. This is discussed in order to shed light on the factors that influence their health and the role that health care providers might play in eliminating existing health disparities. Next, health promotion efforts targeting African American men are discussed. The final section of this review consists of a discussion of what is currently known about the experience of health promotion and the related concept of health for African American men both with and without disabilities.

DEFINING DISABILITY

Throughout the disability movement, the definition of disability has changed many times to reflect social and political ideas and values (Krahn, Putnam, Drum & Powers, 2006; Wendell, 1996). The definition of disability has significant implications for how persons with disabilities are recognized by a society as well as themselves. In their quantitative study examining the experience of becoming disabled, Kelley-Moore and associates (2006), found that disability was associated with negative social stigmas

that influenced when elderly persons considered themselves disabled as well as their perceived level of disability. They also found that societal influences that caused higher *perceived* disability resulted in greater morbidity and mortality regardless of the degree of functional limitation. Further, participants with poorer health commonly reported greater disability. The embodied experience of health potential and limitations appears to have an impact on the health of persons with disabilities; therefore it is imperative for health care providers to understand experiences in the context of disability. This understanding allows greater insight into factors that shape the self image of persons with disabilities, while influencing their health promoting practices.

According to Wendell (1996), the definition of disability, and related concepts like impairment, should "depend to some extent on the physical, social, and cultural environment in which a person is living, and is influenced by such factors as what activities are necessary to survival in an environment and what abilities a culture considers most essential to a participant" (p. 12). In accordance with Wendell, the author asserts that defining disability extends far beyond a person's physical limitations. The definition must first consider an individual's desired level of functioning and quality of life. In addition, societal expectations and barriers along with the resources available to aid in the achievement of those desired levels of functioning should be considered. In essence, the definition of disability is also a social phenomenon instead of solely a biological process. It is important for health care providers to understand how persons with disabilities identify themselves and interact with their environment to ensure that the care they provide is effective, relevant, and accessible. Wendell (1996) asserts that the social construction of disability leads to the development and perpetuation of “cognitive and social authority” (p. 119). She poignantly and candidly discusses the implications of cognitive and social authority among medical professionals in particular:

> The cognitive and social authority of medicine to describe our bodies affects how we experience our bodies and ourselves, how our society describes our experiences, and validates/invalidates them, how our society supports or fails to support our bodily sufferings and struggles, and what our culture knows about the human body. It also affects profoundly the relationship of medical providers to patients and the quality of medical care. It should be remembered that although the authority of medicine affects everyone, healthy or ill, disabled or non-disabled, its consequences are compounded for people who have little cognitive or social authority of their own, and for people who are routinely treated as though they are without such authority, such as most women, and many men who are poor, old, disabled, and/or subjected to racism (p. 119).

It would seem that a narrow definition of disability fails to understand and adequately respond to the needs and desires of minorities with disabilities.

For the purposes of this study, disability is defined by Verbrugge and Jette (1994). They define disability as the inability to perform a socially constructed role such as employee or socialite, secondary to a functional limitation. For example, due to her inability to walk, a woman who finds it impossible to find a job or to care for her family may consider herself disabled. On the other hand, a woman who cannot walk but is able to work and fulfill familial roles may not consider herself disabled although societal standards may consider her so. These two examples suggest that the path to disability is avoidable and individual. Verbrugge and Jette define this personal trajectory towards disability as disablement. According to Verbrugge and Jette the disablement process consists of four stages: (a) pathology, (b) impairment, (c) functional limitation, and (d) disability. The trajectory from pathology to disability is shaped by numerous categories of risk factors and interventions that have the potential to either slow or quicken one's progression towards disability. The development and level of impairment, functional limitation, or disability attained, is determined by the presence or absence of risk factors, as well as the effectiveness of health related interventions. Health promoting initiatives aimed at eliminating preventable conditions and disparities among persons with disabilities has become increasingly important in health care (Krahn et al., 2006). Before

effective health promoting initiatives can be designed, providers must first understand the experience of health promotion in the context of disability. This perspective affords providers the opportunity to discover the health related factors that may prevent or slow an individual's progress towards disability.

INVISIBLE DISABILITY

Invisible disabilities are impairments that are unable to be substantiated or easily validated by another (Matthews & Harrington, 2000). In other words, the impairment may not always be obvious to the onlooker. Invisible disabilities may include chronic pain (Lillrank, 2003), fatigue, or muscle weakness (Stone, 2005). While the disability experience is unique and personal, it also has the potential to become a "social" or shared experience based on societal expectations of what the outward appearance of the disabled body should look like and how it should perform (Matthews & Harrington). When this occurs, an individual may discover that essentially, an aspect of their embodied experience of disability is discounted or perhaps even rejected by the spectator.

I can attest to instances when I have witnessed an individual pull their vehicle into a space designated for disabled parking, get out, and walk seemingly "normally" and unassisted by any accommodative device. I can easily recall the feelings of annoyance that I experienced because I saw no overt evidence of a limitation and felt that those persons were receiving an unfair and undeserved advantage. Perhaps, it is these kinds of reactions and paradigms that contribute to the feelings of shame, humiliation, stigma, and frustration often associated with invisible disabilities (Boyles, Bailey, & Mossey, 2011; Cortés, Hollis, Amick, & Katz, 2002). According to Stone (2005):

> The hegemony of dualistic thinking means that there is the assumption of an unproblematic divide between disabled/abled. Coupled with the belief that decisions about who belongs in which category can be determined with empirical evidence, there is no room for recognizing that those who appear to be abled may nevertheless have unseen difficulties. This dualistic thinking creates a problem for

> those with invisible disabilities, because they do not fit into neatly pre-defined categories. Rather, it is an ongoing condition of their lives that their disabilities are for the most part invisible, but depending on circumstances and environment, their disabilities may become clearly visible.

Like the participants in a study conducted by Butler, Derrett, & Colhoun (2011), persons with invisible disabilities may find themselves with "delegitimized access to the sick role" (p. 2250) because of their inability to "fit" neatly and consistently into a category of disabled or not disabled. They may exist in a space wherein their subjective identity conflicts with the opinion of those around them resulting in a discourse between what resources they need and what resources they *look* like they need in order to function and live. They do not look disabled, so why would they need a disabled parking placard? Why do they require assistance to stand today when they did not need it yesterday? In some instances, these individuals may or may not be able to perform the tasks deemed appropriate based upon the standards of others. Further, others may "notice that they do not do things that are expected, they do unexpected things, or they do things in unusual ways" (Stone, p. 300). In these instances, one's embodied disability experience is negated simply because there is no outward physical evidence of its existence.

The questioning of one's subjective and embodied reality, not only by others, but by themselves as well (Stone, 2005), can lead to feelings of resentment and doubt about one's collective identity (Boyles, 2011; Stone) that may influence how one feels about their body's capabilities, limitations, and potential for health. It stands to reason that private and public struggles to place one's contextualized experience and identity into a "disabled/able-bodied dichotomy" (Thomson, 1997, p. 34), may influence how one treats and cares for their body-a body that serves as the portal through which they come to know and experience the world around them (Husserl, 1999). By endorsing and perpetuating the denial of a person's embodied experience, society renders persons with invisible disabilities marginalized and isolated (Davis, 2005). Davis asserts that persons

with invisible disabilities are marginalized "because those of us who possess socially favored status are self-absorbed or habitually or deliberately inattentive, but also because we actively (though not consciously) employ defensive strategies to protect ourselves from having to acknowledge realities that are frightening or unpleasant" (p. 192). She goes on to say that it is this marginalization that serves as the basis of the stigma and victimization historically associated with having a disability.

Persons with invisible disabilities are unfairly victimized by being made to constantly reveal and/or prove what makes them disabled (Davis, 2005). They are challenged to provide salient evidence of their impairment and limitations even when it may be impossible to do so. For example, chronic pain is difficult to substantiate by physical or outward signs, but its ability to debilitate is no less genuine or legitimate than any other impairment. Having an invisible disability creates a discourse between what an individual believes and knows about themselves and what others perceive based on cursory observations and interactions. This discourse is likely to create situations wherein a person may be forced to deny a part of their embodied experience due to shame or (perceived) stigma (Boyles, Bailey, & Mossey, 2011). According to Thomson (1997), "an invisible disability, much like a homosexual identity, always presents the dilemma of whether or when to come out or to pass" (p. 14).

DISABILITY AND HEALTH

Persons with disabilities typically experience poorer health outcomes than persons without disabilities and are at greater risk of developing secondary conditions associated with chronic disability (Dejong et al., 2002; Harrison, 2006; Iezzoni, 2009). Secondary conditions are preventable conditions that are related to the initial disability (Lollar, 2002). They include physical and mental impairments such as chronic pain, depression, and fatigue (Kinne, Patrick, & Doyle, 2004; Patrick, 1997). Effective health promotion

initiatives designed to prevent secondary conditions among persons with disabilities are needed (Altman & Bernstein, 2008; Kinne, Patrick, & Doyle; Patrick; Ravesloot et al., 2007) to improve the long-term health of persons with disabilities. American adults with disabilities between the ages of 18 and 44, are less likely to exercise and are therefore more likely than adults without disabilities to be overweight and obese (Altman & Bernstein, 2008). In addition, when compared with persons without disabilities, they are twice as likely to be chronic smokers (Altman & Bernstein). Obesity and smoking have significant, negative implications for health and mortality over the life course and can contribute to greater disability over time. It is important for health care providers to understand and effectively address the factors and damaging health behaviors that compromise the health of persons with disabilities.

Despite significant achievements in technology and research, health care entities in the United States remain ill equipped to care for individuals with disabilities (Dejong et al., 2002). When compared to persons without disabilities, people with disabilities are less likely to receive the care that they need or they experience significant time delays in receiving needed care (CDC, 2010; Patrick, 1997). Persons with disabilities commonly cite limited access to transportation, communication services, and financial resources as barriers to obtaining quality health care despite being a majority of health care consumers "in the so-called vulnerable populations" (Dejong et al., p. 262; Tomlinson et al., 2009). Health consumers with disabilities, because they may require additional accommodations and a higher level of care from their medical provider, are often considered nuisances by medical professionals (Dejong et al.); therefore, people with disabilities may not receive the level of care needed to adequately address their health needs. Limited access to, and inadequate health care commonly contribute to poor health outcomes among persons with disabilities (Iezzoni, 2009).

The health of persons with disabilities can be indirectly impacted by the disparities in income and employment that they experience at a much higher rate than persons without disabilities (Brault, 2008). People with disabilities experience poverty at more than three times the rate of people without disabilities (Iezzoni, 2009; Loprest & Maag, 2007). For people who develop a disability early on in the life course, lower educational attainment often results in low earning power and limited employment opportunities throughout their lives (Loprest & Maag). The ability of employment opportunities and educational attainment to determine health is well known (Iezzoni; Beckles & Truman, 2011). According to Beckles and Truman:

> Education is a strong determinant of future employment and income. In the majority of persons, educational attainment reflects material and other resources of family of origin and the knowledge and skills attained by young adulthood. Therefore, it captures both the long-term influence of early life circumstances and the influence of adult circumstances on adult health. Income is the indicator that most directly measures material resources. Income can influence health by its direct effect on living standards (e.g., access to better quality food and housing, leisure-time activities, and health-care services) (p. 13).

Income level and educational attainment are likely to have implications for the type of jobs that persons with disabilities acquire, thereby influencing the level of insurance available to them (Moonesinghe, Zhu, & Truman, 2011). Furthermore, inconsistent health insurance coverage and subsequent limited access to preventative health services contributes to poor health and premature mortality for persons with disabilities (Dejong, Palsbo, & Beatty; 2002; Iezzoni, 2009). Improving access to *effective* preventative care is imperative in order to address the health disparities that are so prevalent among people with disabilities.

DISABILITY AMONG YOUNG ADULTS IN THE UNITED STATES

According to the Centers for Disease Control and Prevention (2008), there are an estimated 54 million Americans living with a disability, and of those, approximately 15.3

million are between the ages of 18 and 44 (CDC). It has been documented that people aging with a disability are at risk for poor health outcomes (Harrison & Stuifbergen, 2001; Dejong, Palsbo, Beatty, 2002; Tomlinson et al., 2009) such as fatigue or chronic pain (Kinne, Patrick, & Doyle, 2004). Although poor health outcomes are common among young adults aging with a disability or a chronic disabling condition (Charlifue, Lammertse, & Adkins, 2004; Sendroy-Terrill, Whiteneck, & Brooks, 2010), there is a paucity of research that specifically explores how people with disabilities might prevent them through the use of health promotion (Krahn, Putnam, Drum & Powers, 2006). Harrison (2006) and Stuifbergen (2006) suggest that effective health promotion interventions targeting persons with disabilities must be considerate of the personal experiences of the individual. This study will provide understanding of the health promotion experience of young adult African American men with mobility impairment, with the hope of one day informing the development of future health promotion interventions.

There is a paucity of literature exploring the underlying factors and experiences at earlier stages in the life course that may contribute to the development of health problems over time for young African American with disabilities. Further, the literature revealed a scarcity of research that provides practitioners with insight into their disablement experience; therefore, a pilot study was conducted by the author, with her adviser's guidance, to explore disablement from the perspective of young adult African American men and women with permanent mobility impairment. In conducting this study, the investigator gained some valuable insight into how these men and women took care of their bodies. The sample consisted of ten participants ranging in age from 22 to 39. In this pilot study, two primary themes were identified: "Cumulative Losses" and "Sustained Desires." The results of this study suggest that despite significant losses of autonomy, identity, financial resources, and intimacy, several human desires remain intact. Among

this group, basic desires for independence, shared intimacy, and psychological and physical health were not diminished by physical limitations and may serve as the impetus for health within illness (Lindsey, 1996) to become possible and even probable for young persons with disabilities.

The findings of this study indicate the level of motivation that young adult African American men and women with disabilities have to improve levels of well-being, as well as their ability to conceptualize the possibility of health promotion within the context of their impairment. Further, findings of this study provide evidence that young adult African American men and women with disabilities not only engage in health promoting behaviors, but desire increasing levels of physical, spiritual, and mental health while living with a disability. In understanding the health promotion experience of young adult African American men with mobility impairment, health care providers will be better able to understand their embodied experiences. Only then, will providers be able to create and offer effective, appropriate health promoting interventions.

Despite their increased risk for poor health outcomes, research studies regarding health care access and quality rarely focus on young adults with disabilities (Callahan & Cooper, 2006). In their study of 599 young adults with and 4571 young adults without disabilities, aged 19 to 29, Callahan and Cooper found that young adults with disabilities without insurance were four times more likely than insured young adults without disabilities to report inadequate health care and no regular source of health care. Further, they discovered that only 40% of participants with chronic disabling conditions had health insurance. At a 36-month follow-up, 56% of the participants in their study reported gaps in health insurance coverage with an average lag time of 15 months. Inconsistent health insurance coverage and subsequent limited access to preventative health services contributes to poor health and premature mortality for persons with disabilities (Dejong, Palsbo, & Beatty; 2002; Iezzoni, 2009).

It is important for health care providers to strengthen their understanding of factors occurring early in the lifespan that may contribute to the development of disparities in co-morbid conditions and mortality among persons with disabilities. An enhanced understanding of their health promotion experience may encourage the creation of relevant, cost-effective health promoting initiatives that can be maintained regardless of insurance coverage status or at little or no cost to insurance companies and health care consumers (Rimmer, 1999). In addition, health promoting interventions are needed that encourage persons with disabilities to take an active role in managing their health (Dejong, Palsbo, & Beatty). To be effective, such interventions must consider the unique life experiences of the targeted population (Stuifbergen, 2006).

OVERVIEW OF HEALTH-WITHIN-ILLNESS

After conducting three different studies exploring the personal experiences of women with breast cancer, Moch (1998) surmised that health-within-illness was "an opportunity which increased meaningfulness of life through connectedness or relatedness with the environment and/or awareness of self during a state of compromised well-being" (p. 305). In other words, health-within-illness is a positive state of personal growth and fulfillment that can simultaneously occur along with illness (e. g. disability or a chronic health condition). Moch describes four essential components of the definition of health-within-illness. The first component refers to the illness state as chance to experience mental, physical, and emotional growth. In the second component, Moch asserts that persons experiencing illness can find renewed meaning in life relationships and mundane life activities that are typically taken for granted. The third component consists of strengthening relational bonds with others through more authentic interactions and perhaps renewed spiritual fervor. The final component involves an increased self-awareness or "self-knowledge" (Moch, 1998, p. 307) of one's body and embodied

experiences in the context of a compromised state of health. In sharing her personal anecdotes, Moch asserts that the final component of health-within-illness may breed empowerment development. As people experiencing illness become aware of their own values and definitions of health, they become better equipped to make decisions regarding their health. The concept of health-within-illness makes it possible to consider persons in a compromised state of well-being, such as a chronic disability, as sufficiently qualified to establish a quality of life reflective of their personal health needs and beliefs (Stuifbergen, 2006).

Health-within-illness becomes feasible when healthcare providers embrace the notion that the body's experiences of health and illness are interconnected and one experience cannot exist without the other (Lindsey, 1996). According to Merleau-Ponty (1945), "Illness, like childhood and 'primitive' mentality, is a complete form of existence and the procedures which it employs to replace normal functions which have been destroyed are equally pathological phenomena" (p. 123). Being that the totality of experiences (i.e. health and illness) depends on each phenomenon being acknowledged and appreciated, and the body being the focal point of all perception (Husserl, 1999), the concept of health-within-illness becomes plausible as a framework for exploring the meaning of the health promotion experience of young adult African American men with mobility impairment.

The concept of health-within-illness stands as a direct affront to the once pervasive belief that for disabled persons, health promotion is seemingly impossible. Healthcare efforts have traditionally focused on preventing further disability or preventing disability all together (Harrison, 2006; Lies & Nowak, 2008; Stuifbergen & Becker, 1994). Among persons with disabilities, this belief can result in a person's identity and self concept being defined by the chronic condition or disability (Lies & Nowak), whereas the concept of health-within-illness offers a more positive, almost

hopeful, perspective of the illness experience (Lindsey, 1996; Moch, 1998). Beliefs about one's potential to realize health may influence the level of motivation to improve levels of well-being, as well as their ability to conceptualize the possibility of health promotion within the context of their impairment. As an individual reflects and shares their experience of health promotion, it creates the opportunity for their health needs to become better understood and more salient.

Health-within-illness emphasizes the *opportunity* to achieve some level of health in the context of illness, thereby rendering the illness state a time of growth and transformation. In her hermeneutic phenomenological study of persons with disabilities and/or chronic illnesses, Lindsey discovered six overlapping components of the concept of health-within-illness. The components or themes she reports are much like the ones described by Moch in an earlier section, but with two notable exceptions: "transcending the self" and "acquiring a state of grace" (p. 468). The first theme, transcending the self, involves escaping the physical constraints imposed by disability by purposefully imagining or picturing one's body freely moving without a disability. Acquiring a state of grace entails a tranquil, profound sense of safety and purpose created by a spiritual awakening. This state is characterized by peace and resignation to one's situation and life with disability. The potential for health and growth is no less realistic for a person with a disability than for one without. According to Lies and Nowak, health-within-illness makes it possible for persons with disabilities to be viewed as capable of living "full and rich lives and not be seen first to be defined by their malady" (p. 346). By changing the way in which persons with disabilities are viewed, the idea of health-within-illness has the potential to shift the focus of health care of persons with disabilities from disability prevention to health promotion in the context of disability (Rimmer, 1999; Stuifbergen, 2006).

The ability to design appropriate health promoting interventions that are likely to be effective requires a more thorough understanding of the health promotion experience of persons with disabilities. In addition, it stands to reason that in order for health promotion interventions to be most effective, they must honor the desires and needs of the people they are designed to help. In their phenomenological study of a young adult college student's experience with health in the context of paraplegia, Lies & Nowak (2008) ascertained that for the young man, it was important for his health care providers to "acknowledge and recognize his need for his voice in his own choices and care plan, and maintain his dignity in moving through the limited circumstances to a place of health and wholeness within illness" (p. 351).

THE HEALTH STATUS OF AFRICAN AMERICAN MEN

Despite health promotion initiatives aimed at decreasing health disparities among minority populations, African Americans continue to experience higher mortality and morbidity rates as well as poorer health outcomes than whites with comparable socioeconomic resources (House & Williams, 2000; Williams, 2003). In comparison to women's health disparities, less attention has been given to men's health and even less to African American men's health (Hatchett, Holmes, Duran, & Davis, 2000). Racial disparities are evident in chronic health conditions. For example, among men in the United States, African American men in particular experience higher rates of chronic diseases such as heart disease and hypertension than non-Hispanic white men (U.S. Department of Health and Human Services, Office of Minority Health, 2007). According to the U.S. Department of Health and Human Services (2007), African American men have the highest incidence and mortality rates for all cancers and are more likely to contract and die from HIV/AIDS than non-Hispanic white men. In addition, they experience a 40% higher incidence of diabetes mellitus, type 2 than non-Hispanic white

men (U.S. Department of Health and Services, Office of Minority Health). On average, African American men are expected to live six years less than African American women and seven years less than non-Hispanic white men (U.S. Department of Health and Services).

In general, African American men in the U.S. tend to "live sicker and die younger" than non-Hispanic white men (Gadson, 2006, p. 488). Typically, disability rates rise as people age and a number of studies have shown that as they age, African American men and women experience higher rates of disability than Whites (Mendes de Leon, Barnes, Bienias, Skarupski, & Evans, 2005; Kelley-Moore & Ferraro, 2001, 2004; Song et al., 2007; Thorpe, Weiss, Xue, & Fried, 2009). Almost 20% of African American men report living with a disability-the highest rate of disability among men when compared to White, Asian, and Hispanic men (U.S. Census Bureau, 2008). In their study of persons at least 50 years of age, Liao, McGee, Cao, & Cooper (1999) found that African American persons experienced the highest incidence of disability and co-morbid conditions in the later months and years of their lives.

There is evidence that for African Americans, having a disability is associated with factors that lead to preventable co-morbid conditions or premature mortality (Centers for Disease Control, 2010; Iezzoni, 2009; Krahn et al., 2006). For example, Chibnall & Tate (2005) found that among African American men and women with disabilities, disability status was associated with inadequate medical treatment and low levels of satisfaction with available medical services. Limited financial resources, low educational attainment, and the absence of health promoting behaviors (e.g., weight maintenance) were related to a greater risk of developing disability among African Americans when compared to Whites in a study conducted by Dunlop and associates (2007). In order to eliminate health disparities associated with disability, it is evident that health promotion initiatives targeting African American men with disabilities are

warranted. Effective heath promotion initiatives aimed at African American men with disabilities, can be designed only after understanding how the health promotion experience unfolds in the context of their "life-world" (Husserl, 1999, p. 353).

In discussing the need to understand their health promotion experience, it is important to consider the contextual factors influencing the health of African American men. The health of African American men is affected by a broad range of social determinants including “residential segregation” (Williams & Jackson, 2005, p. 328), current and future socioeconomic resources, and limited access to effective, quality health care (House & Williams). Beckles and Truman (2011) suggest that African American men and women are at significantly higher risk for adverse health outcomes related to low educational attainment and profound poverty when compared to white Americans. Williams and Jackson assert that the improvement of health promotion and disease prevention initiatives are an effective means of decreasing existing “racial disparities in health” (p. 332). They go on to suggest that health care providers must become better equipped to provide appropriate health care and health promotion programs considerate of the environmental contexts in which African Americans reside therefore, further research is warranted that explores the health promotion experience of African Americans in general (Johnson & Nies, 2005) as well as gender differences (Johnson, 2005).

Several researchers have reported the plethora of health problems that exist among African American men with disabilities in the later stages of the life course (Chumbler, Hartmann, Cody, & Beck, 2001; Kominski et al., 2002; Liao, McGee, Cao, & Cooper, 1999; Miller, Wolinsky, Malmstrom, Andresen, & Miller, 2005); however, there is a paucity of literature exploring the underlying factors and experiences at earlier stages in the life course that contribute to the development of these health problems over time. Further, the literature reveals a scarcity of research that provides practitioners with

insight into the health promotion experience of young African American men with disabilities. This insight may assist healthcare providers in understanding the health needs of young African American men with disabilities as well as facilitate a patient-provider relationship based on a mutual understanding of experience.

MASCULINITY AND HEALTH AMONG AFRICAN AMERICAN MEN

Disparities in the quality of health and health care across racial, ethnic, and socioeconomic groups have been extensively explored and well studied in the United States (Healthy People 2010, 2006). When compared with other racial and ethnic groups, African American men experience the highest number of health disparities. The factors that perpetuate health disparities among African American men are multi-dimensional and include the lack of access to equitable healthcare and the lack of knowledge and limited education about health promoting behaviors (Scott, 2009). Effective health promoting strategies should include careful consideration of these factors in order to be as effective as possible. This section will focus specifically on how masculinity ideology may affect the health, health beliefs, and health behaviors of African American men.

Throughout a man's lifetime, his idea of masculinity frequently evolves based upon the feedback he receives from society that designates what is "acceptable" behavior for young boys and men. Societal expectations dictate how a man should behave both privately and publically. In addition, they provide a blueprint for how a man should behave when engaging with others in all aspects of his life. There are two main types of masculinity. One, hegemonic masculinity (Connell, 1995) characterizes "power and authority" in American society (Courtenay, 2000, p. 1388), while the second, traditional masculinity, stands as an alternative to hegemonic masculinity.

According to Courtenay, society views hegemonic masculinity as dominant over alternative forms of masculinity and all things considered feminine. Within the United

States, hegemonic masculinity ideology is exemplified by heterosexual, White men with the highest levels of education and socioeconomic status (Courtenay). In cases where a group of men lack high social status and levels of perceived power, very often they will alter hegemonic masculinity in order to create a masculinity ideal that they feel is more "valid." While hegemonic masculinity emphasizes the gaining of social status and power, alternative forms of masculinity, including traditional ideals, are focused on confirming their masculinity among those with whom they interact on a day-to-day basis. Because society has historically denied African American men the control, social status, and power normally reserved for educated White males, African American men will often endorse an idea of masculinity that makes the ideals of masculinity more accessible and relevant to them and their environment or situation (Courtenay). According to Liburd, Namageyo-Funa, and Jack (2007), "Over centuries of resistance to the denial of their manhood, black masculinity still emerges in diverse social constructions as equated with physical strength and endurance, pride and control" (p. 552). This researcher is careful not to purport that a singular masculinity exists among African American men, but instead believes an "increasingly nuanced plurality of black masculine identities" (Wallace, 2002, p. 15) to be most accurate.

Defining masculinity from a postmodern social constructionist perspective, involves the idea that gender identity is developed relative to social contexts. Addis and Mahalik (2003), assert that masculinity is a phenomenon constructed and actively carried out as a man navigates in a particular environment or situation. This models permits masculinity ideology to be viewed as ever evolving and "patterns of contextually situated actions that may become more or less likely depending on particular person-environment transactions" (Addis & Mahalik, 2003, p. 9). Masculinity, based on subjectivity, becomes the basis for a man to realize the behaviors that his particular context has deemed "normal" (Phillips, 2006).

The idea of masculinity is likely shaped by a number of things, including life experiences, environment, societal expectations and stereotypes, and cultural norms. Subsequently, the manner in which a man portrays masculinity is influenced by his "age, ethnicity, social class, and sexuality" (Courtenay, 2000, p. 1390; Jack, 2005). Generally, men tend to agree on what is considered masculine, but how they demonstrate or display masculinity depends upon their ethnicity, perceived power, and social status (Courtenay, Majors, 2001). For example, while the idea of "provider" might transcend race and ethnicity, the way in which a man demonstrates provider will be different. One man might interpret provider as someone who pursues financial gain at all cost while another emphasizes emotional support and physical presence.

Research reveals a consistency among marginalized men, such as African American men (and likely includes men with disabilities), exhibiting a "stronger endorsement"(Courtenay, p. 1392) of the traditional idea of masculinity, when compared to non African American men. In a study conducted by Levant and Majors (1997), African American men primarily endorsed the most traditional idea of masculinity. The prevalent endorsement of traditional masculinity has certain implications for health beliefs and behaviors born of this ideal. Traditional masculinity encourages men to engage in behaviors that are detrimental to their health (Courtenay). In addition, health and the pursuit of it may be of lower priority to marginalized men who endorse traditional masculinity ideology. Instead of health, their efforts might be focused largely on their role as family breadwinner.

The bodies of men with disabilities do not coincide with society's image of masculinity (Shuttleworth, 2004, p. 166). Shuttleworth goes on to say that masculinity is a fluid phenomenon based on one's being and identity in the world. Embodied beliefs about masculinity, as well as the embodied experience of it in the context of disability, are likely to be renegotiated and revised based on physical abilities and resources,

personal experiences, as well as personal and societal expectations (Connell, 1995). For example, in his study of masculinity among men with disabilities, Shuttleworth found that for the men in his study, "Disabled masculinity comes to the foreground during their interactions with those to whom they are sexually attracted" (p. 170). According to Connell:

> The constitution of masculinity through bodily performance means that gender is vulnerable when the performance cannot be sustained-for instance, as a result of physical disability (p. 54).

In reconciling notions of masculinity, young adult African American men are challenged to rewrite narratives imposed by society regarding their bodies. Race, disability, cultural ideals of masculinity, and gender stand to influence societal expectations of what the African American male body with impairment should look like and how it should perform in the public arena. The inability of young African American men with invisible disability to meet societal expectations of masculinity stands to create an isolated existence grounded in feelings of abnormality and shame.

The postmodern idea of feminism aids in redefining the concept of “other” or “otherness” (Tong, 1998). The concept of “other” is often examined in the context of race, racism, imperialism and colonialism. Tong states, “The condition of otherness enables women to stand back and criticize the norms, values, and practices that the dominant culture (patriarchy) seeks to impose on everyone-including those who live on its periphery-in this case women” (p. 195). According to Fanon (2008), the citizens who sit on the periphery of society are the victims of colonization, specifically the black male. The inherent component of postmodernism deconstruction encourages one to be able to “see the advantages of *not* being one of society’s favored members-of being excluded, shunned, frozen out, disadvantaged, unprivileged, rejected, unwanted, abandoned, dislocated, and marginalized” (p. 195). Fanon gives insight into his belief that like other

black men, he too has been systematically victimized and shackled by colonialism and racism. Fanon purports that the struggle for liberation will allow the colonized man who has been dehumanized and subjugated to regain his humanity and dignity. Contextualized masculinity provides the means for African American men to create an existence grounded in dignity. African American men internalize and exhibit personalized and fluid masculinity ideals that gives them "a way of surviving in a restrictive society" (Majors & Billson, 1992, p. 2).

Several of the young African American men who participated in the pilot study "Health Disparities among People with Disabilities" shared how their perspectives on what constituted "being a man" had evolved during their transition to disability. Gibbs (2005) discovered this phenomenon in her study of men with chronic arthritis. She found that in some instances, the men in her study not only challenged the socially accepted ideals of hegemonic masculinity, but also their allegiance to it-particularly when its tenets contributed to self-defeating health behaviors and subsequent poor health outcomes.

The ways in which masculinity manifests itself in a man's individual health behaviors depends on a man's personal beliefs about what "being a man" encompasses. While the health behaviors of men have been examined in several studies, very few studies have sufficiently or extensively explored the reasons why men choose to make certain decisions regarding their health. Courtenay (2000) asserts that medical literature has essentially ignored the influence of masculinity on the health and health risks of men. In order to reduce health disparities and risk factors among men, it is imperative to uncover the reasons why men avoid practicing health promoting behaviors. The way and the extent to which a man participates in health behaviors appear to be tied to their perceived level of masculinity (Liburd, Namageyo-Funa, & Jack, 2007). According to Courtenay, health behaviors and beliefs are representations of a man's expressions of gender identity.

The propensity of health disparities depends not only on the overall tenets of a certain type of masculinity, but also on *how* those beliefs are carried out by way of personal behaviors. Some health behaviors considered "masculine" encourage the propensity of health disparities among men. Not seeking health care when ill is a frequent behavior among men overall. Several studies show that African American men are less likely to seek care from health care providers (Abernethy, Magat, Houston, Arnold, Bjorck, & Gorsuch, 2002; Addis & Mahalik, 2003; Millon-Underwood & Sanders, 1990). Acting in the context of a more traditional genre of masculinity, African American men tend to demonstrate their masculinity by avoiding health care and practicing risky behaviors (Courtenay, 2000). Among African American men, this prevalent viewpoint of masculinity emphasizes self-reliance, antagonism against "feminine" behaviors such as symptom acknowledgment, and encourages risky behaviors such as unprotected sex, to demonstrate maleness. Health promoting behaviors that are viewed in a feminine light are frequently opposed and avoided (Courtenay; Mahalik et al., 2007). If health care is to be improved for young adult African American men with disabilities, the author proposes that the way in which health promotion is negotiated and experienced in contextualized masculinity must be explored.

THE HEALTH PROMOTION EXPERIENCE OF AFRICAN AMERICAN MEN

A review of the literature revealed several qualitative studies (Coles et al., 2010; Dumbrell & Mathai, 2008; Hughes, Sellers, Fraser, Teague, & Knight, 2007) exploring the health promotion practices, beliefs, perceptions, and barriers of African American men without disabilities; however, there is a paucity of phenomenological studies exploring the lived experience and/or the meaning of health promotion for young adult African American men with disabilities.

While there may be some similarities, the disability experience differs across different ethnic, racial, gender, and social groups (Devlieger, Albrecht, & Hertz, 2007; Kim & Fox, 2006), so it is important to examine the meaning of health and heath promotion among various subsets of men with disabilities. In her literature review, ranging from 1966 to February 2005, of research articles examining the meaning of health and health promotion among persons with disabilities, Harrison (2006) found eight studies, two of which examined the meaning of health promotion. Further, none of the studies specifically mentioned samples of young adult African American men with disabilities.

While the investigator was unable to find literature exploring the lived experience of health promotion for African American men of any age with invisible disabilities, she did discover a study conducted by Kim and Fox (2006) using a qualitative approach. In their study of the meaning of health among 18 persons with disabilities, they surmised that the meaning of health is shaped by an individual's life experiences and interaction with their environment. Furthermore, they assert that "individuals with disabilities have expertise based on their own life experience and in many respects may be the best managers of their own health" (p. 485). The researcher also found a study by conducted by Nazli (2012) regarding the meaning of health among Turkish citizens with disabilities. She too found that the meaning of health is shaped by one's embodied interactions with the world. These studies support the importance of understanding the health promotion experience as it pertains to being a young adult African American man living with mobility impairment.

Young adult African American men with disabilities are an understudied population with unique health care needs. The author was unable to find any studies exploring their health promotion experience. Furthering the understanding of the health promotion experience may improve the ability to design effective health promoting

interventions considerate of the unique health needs of young adult African American men with mobility impairment. According to Watson and his colleagues (1996), "If health promotion is to be effective then it needs to be sensitive to the ways in which structure (and behavior) are experienced in the everyday life worlds of individuals; the everyday cultural and social locations of health" (p. 163).

HEALTH PROMOTION AIMED AT AFRICAN AMERICAN MEN WITH DISABILITIES

The elimination of health disparities among African American men requires a significant shift in the social and political policies and ideologies currently in place (Williams & Jackson, 2005). Furthermore, health promotion initiatives aimed at African American men should have a holistic scope in order to be most effective (Patrick, 1997; Scott, 2009). Gregg suggests that perhaps in prescribing and encouraging health promotion regimens, health care providers are unable to “appreciate the universe that is another person” or the discourse in meaning that may exist between the health promotion experiences of individuals of varying disability experiences and racial backgrounds (B. Gregg, personal communication, November 23, 2010).

Limited knowledge of the health promotion experiences of African American men with disabilities, might contribute to their limited presence in health promotion research. The researcher was able to find four studies were found that specifically identified African American men and women in their sample (Damush, Plue, Bakas, Schmid, & Williams, 2007; Gitlin, Winter, Dennis, & Hauck, 2008; Goeppinger, Armstrong, Schwartz, Ensley, & Brady, 2007; Ravesloot et al., 2007). Only one of the studies may have included young adult African Americans. Participants in each study were a variety of ages including: a mean age of 79 years (Gitlin, Winter, Dennis, & Hauck), 59 years (Damush, Plue, Bakas, Schmid, & Williams), (64 years with SD $\pm$ 12.78 (Goeppinger, Armstrong, Schwartz, Ensley, & Brady), and 45 years with SD $\pm$ 13.4 (Ravesloot et al.).

The highest percentage of African American participants was 85% (N = 13) in the study conducted by Damush and associates. The study conducted by Gitlin and her associates had a sample that was 46% African American; however, 81% of those participants were women. Gitlin and her colleagues explicitly suggested future health promotion research be considerate of the distinctive needs of African American men with disabilities.

The effectiveness of health promotion interventions depends on their relevancy to the people they are targeting (Kim & Fox, 2006). According to Ravesloot and associates, "Had consumers (participants) not been involved in the early stages of this research, it is unlikely that the relevant issues would have been selected for research" (p. 529). In their study designed to improve mobility and functioning, Gitlin and her colleagues discovered that participants in the intervention group demonstrated significant improvement than those in the control group. Further, they found that white and African American participants receiving the health promotion intervention both experienced similar improvement, in all areas except one. They indicated that whites experienced a slightly higher improvement in activities of daily living performance than did African American participants. According to Gitlin and her associates, similar levels of improvement among African Americans and white participants receiving an individualized health promotion intervention as opposed to "usual care" (p. 745), may have been "due to the focus of the intervention on personal goal identification and introduction of strategies that are tailored to the individual's environmental context and personal preferences" (p. 749). In other words, the intervention respected participants' individuality, lifestyles, cultures, and personal desires and was therefore considered equally effective for both groups. Although no studies reported making systematic efforts to assure that interventions were culturally appropriate specifically for minority participants, all of the studies provide evidence of the importance of delivering effective health promoting interventions to persons with disabilities.

LITERATURE SUMMARY

This study explored an experience that is shaped by the context in which it will unfold; therefore, an exploration of the concept of disability is important. The way in which disability is defined by society, as well as by an individual, impacts their pathway to disablement (Verbrugge & Jette, 1994) and their ability to achieve health in the context of their impairment. Being disabled is associated with the following social determinants of health: lower employment rates, lower economic wealth, lower educational attainment (Iezzoni, 2009; Loprest & Maag, 2007), limited access to quality health care (Dejong et al., p. 262; Tomlinson et al., 2009), and lower rates of insurance coverage (Moonesinghe, Zhu, & Truman, 2011). The link between disability and poor health provides the impetus for health promotion research targeting persons with disabilities.

Having a disability that is not easily substantiated by others can create unique challenges for the person with an invisible disability. An individual may discover that essentially, an aspect of their embodied experience of disability has been dismissed or perhaps even rejected resulting in marginalization and shame (Davis, 2005; Boyles, Bailey, & Mossey, 2011). Persons with invisible disabilities are unfairly victimized by being made to constantly reveal and/or prove what makes them disabled (Davis, 2005). They are challenged to provide salient evidence of their impairment and limitations even when it may be impossible to do so. The frequent occurrence of such phenomenon is likely to color how a person treats and cares for their body.

Research related to disability among young adults reveals that people aging with a disability are at risk for poor health outcomes (Harrison & Stuifbergen, 2001; Dejong, Palsbo, Beatty, 2002; Tomlinson et al., 2009). Poor health outcomes are common among young adults aging with a disability (Charlifue, Lammertse, & Adkins, 2004; Sendroy-Terrill, Whiteneck, & Brooks, 2010). There is limited research that specifically explores how people with disabilities might prevent them through the use of health promotion

(Krahn, Putnam, Drum & Powers, 2006). Furthermore, there is a paucity of research exploring the reasons behind the development of health disparities at earlier stages of the life course. The literature shows that research is needed that contributes to an understanding of the health related experiences of young adults with disabilities. With this knowledge, health care providers will be better able to create effective, appropriate health promoting interventions.

The concept of health-within-illness (Moch, 1998) unites the health and disability experiences. The two experiences are superimposed over each other and can occur simultaneously. The literature suggests that health-within-illness is plausible for people with disabilities and chronic disabling conditions. As Lindsey (1996) discovered, health-within-illness makes the notion of heath promotion within the context of disability probable and expected.

The health of African American men both with and without disabilities warrants attention. African American men without disabilities experience the highest incidence and mortality rates for all cancers and are more likely to contract and die from HIV/AIDS than non-Hispanic white men. In addition, they experience a 40% higher incidence of diabetes mellitus, type 2 than non-Hispanic white men (U.S. Department of Health and Services, Office of Minority Health). African American men with disabilities experience higher rates of morbidities and mortality than African American men without disabilities (Centers for Disease Control, 2010; Iezzoni, 2009; Krahn et al., 2006).

The health of African American men with disabilities is impacted by a number of social determinants of health that result in poor health as they age. Several researchers have reported the plethora of health problems that exist among African American men with disabilities in the later stages of the life course (Chumbler, Hartmann, Cody, & Beck, 2001; Kominski et al., 2002; Liao, McGee, Cao, & Cooper, 1999; Miller, Wolinsky, Malmstrom, Andresen, & Miller, 2005); however, there is a paucity of

literature exploring the underlying factors and experiences at earlier stages in the life course that contribute to the development of these health problems over time.

Limited knowledge of the health promotion experiences of African American men with disabilities might contribute to their limited presence in health promotion research. Three studies were found that specifically identified African American men and women in their sample (Gitlin, Winter, Dennis, & Hauck, 2008; Goeppinger, Armstrong, Schwartz, Ensley, & Brady, 2007; Ravesloot et al., 2007). Only one of the studies may have included young adult African Americans.

The literature revealed several qualitative studies (Coles et al., 2010; Dumbrell & Mathai, 2008; Hughes, Sellers, Fraser, Teague, & Knight, 2007) exploring the health promotion practices, beliefs, perceptions, and barriers of African American men without disabilities. Regrettably, the existence of research exploring the experience of health and health promotion for young adult African American men with disabilities is missing in the literature. Understanding the experience of this group within the context of their "life-world" (Husserl, 1999, p. 353) may provide valuable guidance for the health care providers and researchers designing health promoting interventions targeting this population.

CHAPTER SUMMARY

From this review of the literature, it is apparent that a number of variables provide the impetus for this study of the health promotion experience of young adult African American men with mobility impairment. Included in these variables is the idea of how disability is defined and the potential impact of that definition on the health of individuals with disabilities. Since the study focuses on young adult African American men with invisible disability, literature regarding invisible disability specifically, disability among young adults, and masculinity and health are discussed. Current

literature suggests that the health status of African American men, specifically those with disabilities, warrants an in-depth exploration of how their health needs can best be addressed. Literature was also reviewed pertaining to health promotion and phenomenological research targeting African American men with disabilities.

Chapter 3: Research Design and Methodology

This chapter provides an in-depth discussion of the philosophical background of the research methodology and subsequent methods used for this study. The selected methods include the setting, sample, recruitment, data collection, data management, and data analysis. These will be discussed in detail in the following section as well. Finally, a discussion of the ethical conduct of research will be presented, including issues related to the potential risks to participants.

This hermeneutic phenomenological, qualitative study explored the lived experience and subjective meaning of health promotion for a sample of young adult African American men with mobility impairment and invisible disability. Lived experiences cannot be adequately captured and understood without using a research methodology such as hermeneutic phenomenology. Hermeneutic phenomenology gives voice to the experience and meaning of a phenomenon from the individual's unique perspective; therefore, the use of hermeneutic phenomenology was essential to answering the following research questions:

1. What is the lived experience of health promotion for young adult African American men with invisible disability?
2. What is the essential structure of health promotion from the perspective of young adult African American men with invisible disability?

It is expected that this research will serve as the foundation for a body of research exploring health promotion throughout the lifetime of African American men with mobility impairment.

PHILOSOPHICAL BACKGROUND

In this section, the philosophical perspective will be emphasized as it guided the methodological decisions of this study. The first section will include the philosophical

background behind phenomenology and hermeneutics. The next section will include a discussion of the appropriateness and proposed use of hermeneutic phenomenology as a methodology for the study of the lived experience of health promotion from the perspective of young adult African American men with mobility impairment.

Phenomenology.

Phenomenology is concerned with uncovering the meaning associated with the lived experience of a particular phenomenon. Phenomenology is designed to evoke the characteristics and personal meaning of an experience from a person's unique perspective situated in the context of their life experiences and background. A renewed reflection and consciousness of an experience allows individual meaning to be ascribed to that experience. This newly constructed meaning becomes a part of a person's lived experience and "life-world" (Husserl, 1999, p. 353). Capturing the essential structure of a conscious experience is the focal point of phenomenology and requires researchers to access the "life-world" (Husserl) that is another person through language. The researcher using phenomenology understands that the background (e. g. culture, language, history) of a participant provides a backdrop of underlying meaning for experiences that occur over their life time.

Husserl (1999) believed that the experience of a phenomenon begins with the body, which is considered the starting point for consciously interpreting and understanding one's environment. Husserl went on to assert that what is perceived or actual is created by one's own body. According to Husserl, the body is the epicenter of how we experience our bodies as we purposefully move and navigate through our environment. Like Husserl, Merleau-Ponty (1962) believed "the body is the vehicle of being in the world, and having a body is, for a living creature, to be intervolved in a definite environment" (p. 94). This notion of embodiment is what Husserl describes as

being present in all contexts perceived by one's consciousness. In other words, a person is continually present in their world through their bodies so they have the capacity to be continually aware of the ways in which they use and perceive their bodies.

According to Husserl (1999), the body is invariably conscious of something and this consciousness is focused on a particular object (Toombs, 1993). Husserl asserts that an individual's mind never operates separately from his/her body. He suggests that one's body is ever present and interfacing with one's environment even when the mind is not consciously aware of this process:

> I am conscious of a world endlessly spread out in space, endlessly becoming and having endlessly become in time. I am conscious of it: that signifies, above all, that intuitively I find it immediately, that I experience it. By my seeing, touching, hearing, and so forth, and in the different modes of sensuous perception, corporeal physical things with some spatial distribution or other are *simply there for me, "on hand"* in the literal or the figurative sense, whether or not I am particularly heedful of them and busied with them in my considering, thinking, feeling, or willing. (p. 60)

Human beings do not exist separately from their "life-world" (Husserl, p. 353); therefore, they are constantly creating meaning in and interpretation of their world based on past experiences, current happenings, and culture (Crotty, 2003).

Philosophical Hermeneutics.

Munhall (2007) asserts that hermeneutics is "the theory, rather than the practice, of interpretation" (p. 111). According to Grondin (1994), while hermeneutics began as a technical, theoretical guide for the process of interpretation, it has evolved into a *philosophy* focused on understanding a phenomenon-how a researcher comes to know what they know about human experience. Essentially, hermeneutic philosophy has become more concerned with the nature of understanding than explaining procedures for gaining understanding of an experience (Grondin).

Hermeneutics began as a means for capturing the "true" or most accurate interpretation of God's word and the bible (Grondin, 1994); however, according to Grondin, it became apparent that people were unable to interpret the bible independent of their own personal experiences and biases. Furthermore, biblical scholars struggled to extract a uniform meaning of the bible within a context completely different than the one in which it had been written. Out of this discourse emerged an appreciation for the interrelatedness of historical events and how they are interpreted and influence the understanding of human experiences. Wilhelm Dilthey is credited for incorporating the meaning of historical context into the understanding and interpreting of human experiences (Grondin). As reported by Grondin, hermeneutics became considerate of the historical events that shape the current self and the meaning assigned to lived experiences. Furthermore, the history itself is an object of interpretation by the person recalling historical events. The particular events that are recalled, as well as what is shared about a particular experience are all determined by an individual; therefore, in order to understand the experience of another, a researcher must acknowledge that this understanding begins with a historical context.

"Modern hermeneutics, exemplified by Gadamer" (Grondin, p. 46, 1994), emphasized the philosophical basis behind being in the world and understanding a phenomenon rather than a list of procedures for understanding a particular human experience (Laverty, 2003). In other words, hermeneutic understanding is the *universal* avenue for renewed understanding of experience in any circumstance. The occurrence of history is constant; therefore, the interpretation and ascribed meaning of an experience are continually evolving-for both the participant and the investigator. The understanding of historical experience is a reflection of an individual's values and beliefs at a particular point in time.

According to Laverty, Gadamer asserted that this understanding is only possible through the interpretation of language. In agreement with Gadamer, Grondin (1994) states, "Only in conversation, only in confrontation with another's thoughts that could also come to dwell within us, can we hope to get beyond the limits of our present horizon. For this reason philosophical hermeneutics recognizes no principle higher than dialogue" (p. 124). Language is a person's portal into the "life-world" (Husserl, 1999, p. 353) of another. It is the means by which humans engage with each other and in a sense, become "human" to each other.

USE OF THE METHODOLOGY

Phenomenology is concerned with the "essential nature" (van Manen, 1990, p. 39) of an experience regardless of the environment or context in which it occurs (Husserl, 1999). The philosophical basis of phenomenology allows for the multiple ways in which a person experiences the world to be uncovered and shared while challenging the individual to recover embodied life experiences and usher them from the background of their mind into their consciousness (Husserl). This state of heightened awareness allows insight into a perspective of existing in and experiencing the world for both the individual as well as the people around him/her; therefore, the following philosophical premises of phenomenology guided the methodology of this study: the body is the focal point for discovering personal truths and perspectives surrounding a particular phenomenon, the unique experience of a phenomenon begins with a contextualized, embodied experience, and to understand the experience of another, a researcher must access and appreciate their "life-world" (Husserl, p. 353). The premises will be detailed in the following section. This section will conclude with a discussion of the use of hermeneutic phenomenology as the methodology for this study.

Discovering the *personal* meaning of caring for one's body in the context of disability becomes plausible with phenomenology. Phenomenological studies are useful as they provide an opportunity for study participants to reflect upon, or even perhaps to discover, their associated meaning of a particular experience (Laverty, 2003). Phenomenology provides the means for increasing awareness of embodied experiences as well as the meaning ascribed to those experiences. Using phenomenology to explore the lived experience of health promotion will require the researcher to pull from this understanding of embodiment in order to discover the ascribed meaning and experience of caring for one's body while living with disability. With increasing awareness or consciousness of an experience, comes the opportunity to then express the nuances of a particular experience in a way that others can understand.

As an African American woman studying the health promotion experience of African American men, one might assume that the investigator can speak to their experience due to a shared race and ethnicity. Husserl and Merleau-Ponty would assert that such an assumption would be a serious mistake. An individual can only speak to their own uniquely embodied experience. "The primary responsibility for defining one's own reality lies with the people who live that reality, who actually have those experiences" (Hill Collins, 1991, p. 34). The health promotion experience of African American men with mobility impairment can only be accurately conveyed and interpreted from their own perspective and with their input. It is imperative that health care providers understand how young adult African American men with disabilities perceive and experience embodiment as this understanding can provide awareness into the personal philosophies, rationales and decision making processes involved in promoting their health.

In an effort to understand the contextualized experience of another, an investigator must actively engage with the person sharing their experience.

Phenomenology primarily uses a person's language as the means to access their experiences and their associated meanings. The qualitative researcher recognizes that participants use other means of communication, such as facial expressions, to share their experiences, but spoken words comprise the majority of data in a phenomenological study (van Manen, 1990). Merleau-Ponty (1962) speaks to the importance of language in phenomenology when he says, "There is one particular cultural object which is destined to play a crucial role in the perception of other people: language" (p. 413). Merleau-Ponty goes on to say that it is in dialoguing with another, that the researcher can become conscious of a participant's perspectives and integrate them with his/her own. In a sense, the interpretations and perspectives of the participant are ushered into the "life-world" (Husserl, 1999, p. 353) of the researcher where they are interwoven into the fabric of their own personal history and background. The words spoken by participants become a welcomed object of their consciousness. Participants in this study were limited to men able to convey their lived experience of health promotion using spoken language. In order to devise meaning from those words used to describe the health promotion experience, interpretation of that phenomenon and its embodied context was necessary.

In an effort to gain a richer understanding of a phenomenon, an investigator can interpret participants' perceptions and perspectives of their experiences along with the specified phenomenon using hermeneutic phenomenology as a methodology. It is through an examination of spoken and written language describing a particular phenomenon that the researcher recognizes that the totality of an experience is meaningful and relevant although individuals may not be fully cognizant of the total experience or may recall an experience in another way at different times. An individual's experience is different from another's because the experiences and surrounding contexts of no two bodies is identical. How an individual recalls an experience will be different than another's due to diverse histories, values, and beliefs. Further, one cannot perceive

an entire person's identity or the embodied richness of their experiences in the same manner as the individual (Husserl, 1999). Researchers and health care providers must attempt to sensitize themselves to the total experiences for the sake of understanding a phenomenon and improving how related care is provided. Husserl suggests that a shared "horizon" (p.61) of an experience is possible between an individual and another entity (e. g. another person or society as a whole). It is for this reason the investigator was able to explore the phenomenon of health promotion and how it was perceived and experienced by African American men with invisible disability.

Understanding the health promotion experience of young African American men with invisible disability stands to enlighten and modify societal perceptions of what an individual with impairment has the potential to achieve. The author is hopeful that the use of hermeneutic phenomenology in this study will "arouse emotion and motivate to action" (Harrison, Stuifbergen, Walker, Scott, & Choban, 2011, p. 155). It is the author's sincere hope that through the renewed consciousness of their bodies, young African American men with mobility impairment would spur a renewed societal consciousness and enlightenment regarding perceptions of the body with impairment. It is possible that with a greater understanding of their contextualized experience, health care providers may be better able to discourage individual, professional, and societal perceptions that perpetuate disability.

Hermeneutic phenomenology allowed for a contextualized understanding of health promotion for young adult African American men with mobility impairment. The context surrounding an experience includes race, gender, and environment; all of which had the capacity to influence the lived experiences of these young men with disabilities (Ostrander, 2008). Hermeneutic phenomenology allowed the investigator to assume that the health promotion experience of young adult African American men was shaped by their embodied life circumstances and was therefore a unique experience. Exploring

health promotion from the perspective of young adult African American men with mobility impairment and invisible disability provided the opportunity to discover comprehensive insight into their unique experience of health promotion. This insight may give health care providers understanding of how and why they make decisions regarding the care of their bodies. Furthermore, uncovering the meaning of the health promotion for these young men provided another perspective in understanding the concept of health promotion and may broaden the scope of health promoting interventions targeting young adult African American men with mobility impairment.

METHODS

This section includes a discussion of the methods and procedures followed in the conduction of this study of the lived experience of health promotion for African American men with invisible disability. The study's design, procedure for selecting participants, data collection, management, and analysis, as well as measures to allay risks to participants are detailed in this section.

Design.

This study used a non-experimental, descriptive design. Hermeneutic phenomenology guided the data collection, data analysis, and presentation of findings (Cohen, Kahn, & Steeves, 2000). This qualitative study explored the lived experience of health promotion for young adult African American men with invisible disability and mobility impairment and provided a description of the essential structure of health promotion from their unique perspective.

Setting.

The site for this study was concentrated in Travis County but extended to several contiguous counties in the Central Texas region such as Bell, Harris, and Williamson. Travis County includes the city of Austin, TX. The U.S. Census Bureau (2009) estimates

that there are 1.7 million persons living in the Austin metropolitan area and among these, 53.7% are between the ages of 18 and 44. According to the 2006-2008 American Community Survey (U.S. Census Bureau), Austin is comprised of 63.7% White, 35% Hispanic, and 8.2% African American.

Participants were interviewed twice at a mutually decided upon location to ensure the privacy and comfort of participants. Interviews often took place either in their homes or at the school of nursing which aligned with prior experience in the pilot study "Health Disparities among People with Disabilities" that suggested that data collection would most often take place in participants' homes or the school of nursing private meeting rooms.

Sample.

Recruitment.

Potential participants were recruited primarily using the following methods. The sample was selected using purposive sampling. Purposive sampling indicates that participants were chosen according to a pre-determined set of inclusion criteria (Holloway & Wheeler, 2002). First, community liaisons were contacted by the investigator. Liaisons were asked if they knew of potential participants who might be interested in participation. Second, health care and social services agencies that provide services for persons meeting the study's inclusion criteria were visited. Study materials, specifically, information flyers and participant return envelopes were left at the sites. The researcher also visited local African American churches and presented the study's goals to parishioners and left study materials. In addition, the researcher visited local barbershops and salons to talk to patrons about the study and post study information. The investigator visited local gyms and post offices and posted study materials. In addition, ads were placed on community information sites as well as Craig's list. Last, the investigator

distributed flyers via email to UT Austin student and faculty list-serves, such as the Black Graduate Student Association, the KNOW events calendar, the Association of Nurses in Graduate School, and the Black Faculty and Staff Associations. All study materials clearly stated the eligibility information and contact information for the investigator. Interested participants initiated contact by calling or emailing the investigator. Upon receipt of a phone call or email, the investigator explained the study and obtained participants' verbal agreement to participate. Upon receiving verbal consent, the initial meeting was scheduled. Participants were provided a copy of the written consent at the time of the first meeting. At each meeting, each participant was given $20 in cash.

Inclusion Criteria.

The purposive sample consisted of young adult, English-speaking, non-institutionalized, African American men with mobility impairment between the ages of 25 and 39 years of age (Arnett, 2000) living in the Central Texas metropolitan area. Young adult African American men who had no known cognitive impairments severe enough to significantly impede their ability to participate in the interviews were included in this study. Participants must have reported mobility impairment and reported at least two (out of four) of the functional limitations listed below.

As some researchers have suggested (Hammond, Young, & Kidao, 2004; Hehir et al., 2008), it is possible that the adoption of health promoting practices is influenced by factors present during the initial diagnosis of a chronic, disabling condition. A person's early emotional response and health beliefs related to their new diagnosis may affect the development of health promoting behaviors; therefore in order to gain an accurate picture of their health promotion experience, participants must have had a permanent mobility impairment of at least six months duration. Efforts were made to select participants who represented varying backgrounds and a broad range of disability experiences (e.g. age at

onset/occurrence of impairment, pathology type, and socioeconomic status). To be eligible, participants must have reported difficulty or inability to perform 2 out of 4 functional limitations identified in the National Health Interview Survey (2010): (a) walk a quarter of a mile, (b) walk up 10 steps without resting, (c) stand for 2 hours, or (d) stoop, bend, or kneel (U.S. Department of Health and Human Services, 2010).

Sample Size Estimation.

The sample size is based on data quality and study design (Morse, 2000). A sample size of 10 was estimated based on the preliminary study where male participants spoke at length regarding their health promotion experiences and provided detailed, overlapping data from a small number of participants. In addition, the proposed sample size was based upon methodological suggestions supporting fewer participants when multiple interviews are done with each participant (Morse). This study included two interviews which added to the amount of data collected thereby reducing the need for an increased number of participants. Participant recruitment continued until saturation was reached.

Saturation.

In phenomenology, saturation is reached when there is sufficient data to capture an experience in its entirety (Cohen, 2000). At the conclusion of each interview, the investigator wrote in-depth fieldnotes regarding preliminary findings and interpretations. Recruitment and data collection stopped when fieldnotes showed repetitive patterns of experience and when interviews ceased to provide new perspectives on the experience of health promotion. The investigator discussed findings with her adviser to verify saturation as well as her dissertation committee members. In addition, the investigator recruited two additional participants after saturation was obtained to ensure completion.

Interviews were scheduled two to four weeks apart to allow time for investigator reflection of shared stories, unless participants requested an alternative timeframe.

Data Collection

Qualitative data was collected using three methods: qualitative interviews, demographic questions, and fieldnotes.

Qualitative Interviews.

In depth, semi-structured, audio-taped interviews were completed with each participant during two meetings that focused on soliciting participants' feelings, perceptions, and experiences surrounding health promotion. Due to its dynamic nature, health promotion was captured using a prospective approach (Cohen, Kahn, & Steeves, 2000). This approach was used to solicit rich details of the meaning and experience of health promotion for young adult African American men with mobility impairment. Both open-ended questions and back-up probes were used for this study. (See Appendix A) Accommodations, such as using a private room, were made to protect the privacy of participants during interviews.

In an effort to lessen the possibility of undue distress and/or fatigue during this study, qualitative data collection occurred over two interviews. There is notable rationale for the use of multiple interviews to gain insight and establish rapport; Harrison (2006) used up to 4 interviews with a group of older women with significant functional limitations related to polio. Harrison was able to conduct multiple interviews and cover all needed content at a pace established by the participants. This avoided undue stress that could occur by trying to cover all content areas in one visit. The use of multiple interviews is also consistent with the classic recommendations of Seidman (1991) who recommends that multiple interviews be done to establish a relationship, which may provide richer data than when only one interview is conducted. The investigator was

grateful for the additional opportunity for clarification and explanation that second interviews provided.

There can be challenges when interviewing men due in part to the ways in which they display their ascribed masculine ideology, individual identities and their cultural beliefs during the interview process (Schwalbe & Wolkomir, 2003). While differences in race and gender between the interviewer and participant can possibly influence the power dynamics of the interview situation, these differences should not prevent the participant from sharing information that might be considered sensitive if the investigator takes certain steps to facilitate effective communication (Rubin & Rubin, 1995; Yong, 2001). For this study, these steps included establishing and maintaining rapport and trust with participants by approaching interviews as more of a conversation and minimizing any inequalities in class or social position between the investigator and participant by allowing participants to have partial control over the flow, timing, and location of interviews (Yong). For example, participants were given interview time slots to choose from and interviews were scheduled when most appropriate for the participant. In addition, participants were reminded that they were at liberty to end an interview at any point for reasons they deemed appropriate. Each interview lasted from approximately 30 to 90 minutes. Interviews were scheduled two to four weeks apart unless participants indicate that more time or less time was needed.

Demographic Questions.

In addition to in-depth interviews, a demographic tool was used to describe my sample. Please see the Appendix B for detailed types of data collected. Demographic data included age, income, health insurance coverage status, marital status, and employment status.

Data Collection Sequencing.

- ***Meeting 1:*** This meeting began with the investigator establishing rapport, reviewing the consent form, answering questions, and gaining written consent. Next, the investigator completed demographic questionnaire. Demographic questionnaires were completed by the participant or with the investigator's assistance. The investigator began the interview process, allowing it to progress according to the participant's preferences. At the conclusion of the interview, the investigator scheduled the next interview. After the interview was completed, the investigator wrote fieldnotes and reviewed study goals in preparation for the next interview.
- ***Meeting 2:*** This meeting began with the investigator answering any questions and establishing rapport. Next, the investigator conducted the individual interview. The investigator discussed her initial interpretations and understanding of the participant's first interview data. Efforts were made to clarify and discuss insights provided by the participant in the first interview. The investigator also reviewed study goals and thanked each participant for participating. Once the interview was completed, the investigator wrote fieldnotes regarding the events of the meeting.

Data Management.

Audiotapes of participant interviews were transcribed verbatim within one week after the interviews and verified for accuracy with the taped interview by the investigator. If questions arose after reviewing the transcripts, the participant was asked to clarify at the next interview. After the final interview, the men were called for clarification only if they consented to future follow-up, which all participants did. Code numbers were assigned to each participant and no identifying data (e.g. names or ages) was assigned to data. Transcriptions were edited for accuracy and all identifying data was removed. Audio recordings were labeled with code numbers and secured in a locked file cabinet.

This locked file cabinet was only accessible to the investigator and her adviser. After checking the tapes against the final transcriptions for accuracy, audio recordings were destroyed (deleted). Signed, written consents were stored separately from audio recordings, transcriptions, and demographic tools in locked file cabinets.

Data Analysis.

Demographic data was entered into Statistical Package for the Social Sciences (SPSS) 20.0 for statistical analysis. Descriptive statistics were used to summarize the demographic makeup of the sample. Demographic information included age, self-reported income, and health insurance coverage status. Please see Appendix B for detailed types of data collected. Data was checked for accuracy using an Excel comparison process before being entered into SPSS 20.0. Demographic information was entered separately into two different Excel worksheets and compared to each other. Discrepancies between the two were highlighted and re-checked by the investigator. Corrected data was presented on a new Excel worksheet. Datum from the verified (third) worksheet was copied and pasted into SPSS 20.0.

Qualitative datum was analyzed using the process outlined by Cohen, Kahn, and Steeves (2000). The planned data analysis steps were organized into six steps: preliminary interpretation of interview data, data immersion, data reduction, line-by-line coding, grouping of unit meanings into categories, and grouping of categories into themes. Each step is discussed below. In addition to interview data, fieldnotes were used at each stage of data analysis.

Extensive fieldnotes were written after each interview and used to capture information that was unable to be captured by interviews alone such as participant attire, body language, facial expressions, environment, and preliminary interpretations and impressions (Cohen, Kahn, & Steeves, 2000). Participants were notified at the time

informed consent was gained that notes on observations such as dress, body language, assistive devices, and environmental details, as well as theoretical observations and documentation of self-evaluations of the interview, were to be written in the field notes. According to Cohen, Kahn, & Steeves, “fieldnotes constitute the story of the researcher’s experience of inquiry, and serve as a record of the researcher’s own construction of meaning” (p. 66), hence a detailed record of fieldnotes was completed.

As a novice investigator, the researcher can admit that, initially, the difference between her research questions was difficult for her to grasp. The researcher's adviser would consistently address this confusion by referring her back to the philosophical basis of hermeneutic phenomenology. The researcher would read and read..and read about phenomenology and hermeneutics only to walk away at times more confused than before. In an effort to "think more phenomenologically," one day the author decided to examine and explore her own embodied experience of a phenomenon. She chose love. During this exercise, she was able to ascertain that for her, the basic components or structure of love consisted of sacrifice, patience, and kindness; however, it also became clear that because of her past and present life experiences, the *meaning* and experience of love was so much more than that. Experiencing love involved the ushering in of vulnerability. Love felt like a place where her authentic self could safely reside in its transparency. Love was a balm for her wounded soul.

At the conclusion of that exercise, it was easier to understand why two separate research questions were needed for this study of the lived experience of health promotion. The constructed essence and meaning of love were both born out of the researcher's embodied, conscious experience of being in this world. They had been shaped by every aspect of the researcher's life including her past, present, and future selves, yet the meaning of love had arisen out of a deeper, individualized comprehension and interpretation. It is the investigator's hope that her simple example of a cursory use of

hermeneutic phenomenology will assist the reader in discerning the aims of this study: The data analysis process unfolded using the following steps:

1. ***Preliminary interpretation of interview data.*** Hermeneutic understanding is the universal avenue for renewed understanding of experience in any circumstance. The occurrence of history is constant; therefore the interpretation and ascribed meaning of an experience are continually evolving-for both the participant and the investigator. The first step of data analysis began during the interview process wherein the researcher actively listened to what the participant was saying and made initial interpretations of what was said. The investigator sought verification of these interpretations from the participant as well as her dissertation committee members. This was an appropriate step to begin evaluating the quality of collected data, so that changes could be made early in the data collection process if needed. After sharing initial interview data with the investigator's dissertation chair, it was suggested that the investigator allow the participant more control over the interview process. In essence, the investigator was encouraged to allow participants to "drive" the interview process with less interference from the investigator. Participants were encouraged to allow their embodied experiences to unfold at their own pace as well as expound on shared experiences and provide as much detail regarding those experiences as they possibly could. These practices resulted in much richer data in subsequent participant interviews.
2. ***Data immersion***. It is unlikely that the meaning of an experience can be ascertained in a single reading of a transcript; therefore, in this step, the investigator reviewed interview transcripts several times and made preliminary interpretations of the primary, underlying "characteristics" (p. 76) of each interaction with the participant. To get a sense of the "whole" and enhance my preliminary understanding of the meaning ascribed to their health promotion

experience, I frequently moved between and around what participants had shared. I spent considerable time in this process until confident that I was sufficiently open and sensitive to all possible aspects of their experiences.

3. ***Data reduction***. In this phase of analysis, data was pared down and grouped based on similar interview topics. The investigator carefully decided what data was useful and what might be considered extraneous details. Very little data was omitted during data reduction because the investigator came to realize that the words spoken by these men were evidence of their conscience existence. The investigator did not want to understand health promotion based solely on her own preconceived notions of the essence of the experience, but also wanted to understand and appreciate what the experience meant for her study's participants. From an interpretive perspective, the investigator believed that the men in this study can never exist separately from their bodies; therefore, a great majority of shared stories, anecdotes, and descriptions are relevant to how they define and understand health promotion because it is this interface between one's body and environment that creates an awareness of the ways in which they manipulate, perceive, and care for their bodies. It is the investigator's belief that these experiences gave context to the motivations and desires to do or not do certain things to their bodies. Topics of discussion deemed unrelated to the health promotion experience were not included in subsequent steps of the data analysis process. For example, one participant went on a tangent about how investing in coffee would be a wise and prudent investment. This data was not analyzed per se, but it was certainly considered and appreciated during the data analysis process as it gave context to this participant's health related choices. The participant's phrases regarding perceived barriers to exercising and getting needed medical treatment was designated for further, more in-depth analysis.

4. ***Line-by-line coding***. This step involves a process wherein meaning units were identified and labeled (in pencil) in the margins of the interviews. The researcher used words as close as possible to those used by the participants themselves.

5. ***Grouping of meaning units into categories.*** Similar unit meanings or labels were grouped into like categories.

6. ***Grouping of categories into themes.*** In this step, the investigator grouped categories into themes. A theme can be thought of as a thread that is interwoven into each similar category. The investigator engaged in constant reflection and collaboration with her adviser to ensure the discovery of "aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (van Manen, 1990, p. 107). In other words, the investigator carefully considered her biases and acknowledged their existence as they could have potentially influenced the uncovered meaning of the health promotion experience. Essentially, throughout the research process, the investigator expected the same openness from herself that she received from study participants. While the steps of data analysis are listed in order, the process was more circular in nature-as is common in hermeneutic phenomenology, with the investigator often moving back and forth between steps (Laverty, 2003). In addition Crotty (2003) speaks of the hermeneutic circle that researchers use during the analysis process to understand "the whole through grasping its parts, and comprehending the meaning of parts through divining the whole" (p. 92). The investigator moved in a cyclical fashion, like the one portrayed in Figure 1, in comparing the parts of the phenomenon to the whole in an attempt to fully understand the phenomenon.

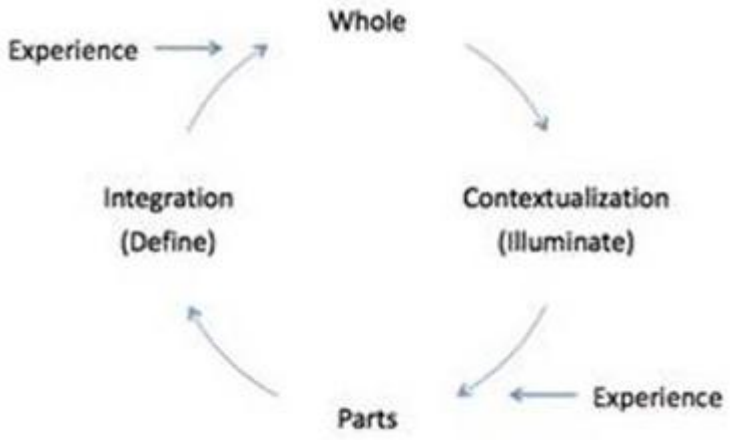

Figure 1: The basic form of the hermeneutic circle (reproduced from Bontekoe, 1996, p. 4)

The investigator had preliminary training in qualitative descriptive analysis during her pilot and assisted in final dissemination of findings from a study of women with polio using hermeneutic phenomenology (Harrison, Stuifbergen, Walker, Scott & Choban, 2011); however, the investigator recognized that qualitative descriptive analysis is quite different than the hermeneutic phenomenological analysis process. In a qualitative descriptive study, a researcher will "stay closer to their data and to the surface of words and events" (Sandelowski, 2000, p. 336) than a researcher who is conducting a phenomenological study.

Using hermeneutic phenomenology, the researcher was prepared to delve deeper into the ascribed meaning behind chosen language and behaviors from the contextualized perspective of each participant. The interpretive process allowed the subtle nuances of meaning to be uncovered. Along with text, detailed fieldnotes were read both separately and together with transcribed interviews. This was done to encourage each component of the interpretation and analysis processes to inform the other. Cohen, Kahn, and Steeves (2000) suggest that during interpretation, "the smallest statements must be understood in terms of the largest cultural contexts (e. g. the community)" (p. 73). The importance and

relevance of every state of being was recognized by the researcher. Further, the investigator understood that relevant data from each participant interaction had to remain intimately connected to the phenomenon both individually and collectively.

METHODOLOGICAL RIGOR

The rigor, or trustworthiness, of this hermeneutic phenomenological study was accomplished using the proposed framework of de Witt and Ploeg (2006). The proposed framework is specific to interpretive phenomenology and includes the following "expressions" (de Witt & Ploeg, p. 216): balanced integration, openness, concreteness, resonance, and actualization. Balanced integration was accomplished by a consistent use and presence of the chosen philosophy's underpinnings in the study's data analysis process and findings.

The expression of openness involved the maintenance of a transparent record (reflexive journal) of when and how data analysis decisions were made. The reflexive journal became a delicious avenue for the researcher to acknowledge and witness her fears, apprehensions, and growth during the hermeneutic interpretive process. The journal became a source of welcomed discovery and helped make unfamiliar territory a little less daunting. When the researcher learned to embrace transparency and critical reflection, she began to pour honest thoughts and raw interpretations into journal. When she "let go," themes and sub-themes became clearer. It helped move what was once obscure to the foreground of her consciousness.

The concept of concreteness involves the presentation of study findings in a way that demonstrates an overt appreciation for the context surrounding an experience. Resonance speaks to the "experiential effect" (de Witt & Ploeg, p. 226) on the person reading a study's findings and might be described as the moment wherein the reader feels a profound and very personal identification with a study's findings. Finally, actualization

refers to the ongoing, undocumented analysis of a study's findings by future readers and the enduring resonance of those findings.

In an effort to counteract preconceived notions and gather relevant, rich data, the researcher maintained an attitude of open-mindedness during data collection and analysis regarding the phenomenon of health promotion among my selected sample. During a discussion of her study of women with breast cancer, Cohen (2000) refers to the "fresh perspective" (p. 3) of the phenomenon of body image that was allowed to emerge only because she did not allow her own preconceived ideas to stifle her participants' perspectives. Jean-Paul Sartre uses an analogy of art that can be used to affirm the importance of approaching the study of a phenomenon with an open mind:

> Having said that, may I ask whether anyone has ever accused an artist who has painted a picture of not having drawn his inspiration from rules set up *a priori?* Has anyone ever asked, "What painting ought he to make?" ...It is clearly understood that there are no *a priori* aesthetic values, but that there are values which appear subsequently in the coherence of the painting, in the correspondence between what the artist intended and the result. Nobody can tell what the painting of tomorrow will be like. Painting can be judged only after it has once been made...we understand quite well that he (Picasso) was making himself what he is at the very time he was painting, that the ensemble of his work is embodied in his life. (pp. 42-43)

As is the case with participants, the researcher is unable to separate themselves from the inherent influence of their past experiences; therefore, both the researcher and the participant became "co-investigators" in the sense that they were partners in the interpretive process. According to Crotty (2003), "we cannot be described apart from our world, just as our world-always a human world-cannot be described apart from us" (p. 79). The lived experience of health promotion is influenced by the life experiences and perceptions of the individual; therefore, a sincere effort was made to capture and understand their contextualized experience. In addition, the investigator completely immersed herself in the data to capture the essences of the participants' experiences.

PROTECTION OF HUMAN SUBJECTS

The proposed study commenced following the review and approval of the University of Texas School of Nursing's Departmental Review Committee (DRC) and Institutional Review Board (IRB). The protection of participants was diligently followed. Written, informed consent was obtained prior to participants' enrollment and participation in the study and included complete disclosure of their rights including to not answer questions, to stop the interview at any point, to withdraw from the study at any time, and to have data remain confidential.

Identifiable information was removed from data. Data was only made available to the investigator, her adviser, and dissertation committee members. Code numbers were assigned to each participant. When participant information was transported for interviews, single files that included name and address were removed for transport and all information was kept in a locked briefcase except when in use. After data was collected, the following procedures were used to protect participant confidentiality:

- Audiotapes and transcripts were labeled with a pseudonym that was used throughout data analysis and dissemination.
- No actual names ever appeared anywhere other than the informed consent document.
- The informed consent document was stored in a locked file cabinet separate from the audiotapes and transcripts with only a coded link available to the investigator.
- Transcripts were edited to delete any identifying information.
- The investigator signed a pledge of confidentiality.
- Data are primarily reported in the aggregate. When individual cases are described, details of the person's life were edited to obscure identification.
- After checking the audio recordings against the final transcriptions for accuracy, the audio recordings were destroyed (deleted).

RISKS TO THE SUBJECTS

There were no foreseeable physical risks for participants in this study; however recalling certain life events did occasionally cause participants to appear sad and tearful. No participants became emotionally distressed to the point of needing intervention, nor did they voice the need for counseling or additional support services. Two participants reported fatigue during one of their interviews because one had worked 12 hours the evening/night prior to the interview and had been unable to rest and the other had just arrived home after international travel. Both participants were frequently reminded that they were at liberty to not answer certain questions and they could have ended the interviews at any time. The investigator also offered to reschedule the interviews at a time convenient for the participants. On each occasion, the participant declined to do so. No invasive procedures were included in this study. Several participants were very candid and open in discussing recreational use of illicit drugs; however, the data obtained did not expose the participant to any social or legal risk. Participants completed questionnaires at the beginning of the first interview. Occasionally participants asked for and received assistance in reading questionnaire items. Also, if needed at that time, the investigator assisted each participant by completing any or all written documents.

There was a plan in place in case participants required medical attention while participating in the study. The investigator, a registered nurse who is trained in basic life support, was alert to any medical distress causing the need for intervention. There were no such occurrences during this study. Further, there were no disability related problems that needed addressing at any point during this study. One participant requested and was provided information regarding smoking cessation programs in the local community.

The investigator was trained in procedures to respect the rights of human subjects. Confidentiality was carefully protected through the use of coded interviews and questionnaires. Participants' names and addresses were kept separate from data. Once

second interviews were completed, participant names and identifying information were destroyed by shredding. All identifying information, such as names, locations, relatives or the like, were deleted from the transcribed data.

INCLUSION OF WOMEN AND MINORITIES

Only African American men with disabilities were included in this study because men and women have differing views of disability and each group's beliefs must be carefully conceptualized independently of the other in order to fully understand their experiences. Preliminary pilot data from both men and women ("Health Disparities among People with Disabilities," NIH/NINR, R01 3NR010360) indicated that young adult African American men and women differed in how they viewed their bodies. Harrison and Stuifbergen (2005) conducted a study wherein women with childhood onset polio discuss their experience with aging across the life course. Much like the participants in Harrison and Stuifbergen's study in describing their experience during young adulthood, female participants in the pilot expressed an appreciation for their current physical abilities. A 23 year-old woman with osteogenesis imperfecta said:

> After that I sucked it up and was like, "Ah, this is my life." It's not like I can't get up. And I can go to Disneyworld, I can go to-I have friends, I have good friends. I am in school. I could get a job. I can, at least I can feel. I was like, there's so many other people who are paralyzed, who can't talk, who can't even comprehend what today is. So then I got over it. And then just been like, "Ah, this is my life."

While there may be some similarities, the disability experience differs across different ethnic, racial, gender, and social groups (Devlieger, Albrecht, & Hertz, 2007). This hermeneutic phenomenological study provides a broader understanding of the disability experience of African American men with mobility impairment. As men and women age, Hatch (2000) asserts that the complexities of life course trajectories differ among genders. Harrison and associates (2008) found that in order to capture ethnic and

gender specific commonalities, researchers must thoroughly conceptualize the findings from each group. This can be done sequentially in independent studies or comparatively in one study after carefully studying each independently. Due to limited dissertation related time and resources, the investigator decided to begin this exploration of disability with African American men.

The degree of *unique* risk within African American men also necessitates their individualized study. The study of women will be included within the investigator's career trajectory. Like career and relationship decisions (Arnett, 2000), the factors that influence the development of sustained health promoting behaviors over the life course begin to appear in childhood and adolescence (Pender, Murdaugh, and Parsons, 2006). Courtenay (2000) asserts that American women consistently adopt healthier beliefs and behaviors than American men. African American men in particular tend to avoid health promoting behaviors (Courtenay), experience worse health outcomes, have disparate access to quality healthcare and treatment (Williams & Collins, 2002), and report the highest rate of disability compared to White, Asian, and Hispanic men (U.S. Census Bureau, 2008); therefore, understanding the health promotion experience from the unique perspective of African American men seemed warranted. It is further asserted by Knodel & Ofstedal (2003) that "gender-specific influences that disadvantage men with respect to survival and health should be addressed just as those that operate to women's disadvantage deserve attention" (p. 687).

Further, given the need to study health promotion based upon young adulthood, a time when health promotion beliefs become more stable while more profoundly effecting long-term health outcomes (Arnett, 2000), children were not included in this study. This study only included young adult African American men between the ages of 25 and 39 years of age.

TARGETED ENROLLMENT

Eleven young men were recruited within the greater Austin metropolitan area. Potential participants for the study were purposefully recruited and interviewed based upon ethnicity, gender, impairment and age. African American men were selected based upon the following inclusion criteria:

- African American race/ethnicity
- Between 25 and 39 years of age
- English speaking
- Residing in the community
- Permanent mobility impairment that limits ability to perform activities. Such as inability to:
    1. Walk 10 steps without resting,
    2. Walk a quarter of a mile,
    3. Stand for roughly 2 hours,
    4. Stoop, bend, or kneel.

CHAPTER SUMMARY

This chapter includes a discussion of the philosophical and methodological framework used in this study. Hermeneutic phenomenology was chosen as the appropriate methodology to interpret the lived experience of health promotion among young adult African American men with mobility impairment. Hermeneutic phenomenology was used to give voice to their personal and contextualized experiences. This chapter included a clear, procedural outline for recruitment, participant selection, data collection, management, and analysis.

Chapter 4: Findings

"Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.' " Mary Anne Radmacher

The purpose of this hermeneutic phenomenological, qualitative study was to explore the lived experience and subjective meaning of health promotion for a sample of young adult African American men with mobility impairment and invisible disability. Lived experiences cannot be adequately captured and understood without using a research methodology such as hermeneutic phenomenology; therefore, the use of hermeneutic phenomenology was essential to answering the following research questions:

1. What is the essential structure of health promotion from the perspective of young adult African American men with mobility impairment?
2. What is the lived experience of health promotion for young adult African American men with mobility impairment?

Data were collected using one-on-one, face-to-face interviews and fieldnotes. In addition, demographic data were collected to provide contextual information regarding the participants' statuses at the time this study was conducted. Hermeneutic phenomenology guided the data collection, data analysis, and presentation of findings (Cohen, Kahn, & Steeves, 2000). The six steps of the data analysis process outlined used in this study were: preliminary interpretation of interview data, data immersion, data reduction, line-by-line coding, grouping of unit meanings into categories, and grouping of categories into subthemes and themes (Cohen, Kahn, & Steeves). This chapter will begin with a collective description of this study's participants. Any potentially identifying information has been altered to protect their identity.

SAMPLE DEMOGRAPHICS

A total of 11 men participated in this study. Sample demographics are described in Table 1. The mean age of the participants was 32.4 years. The average age of impairment onset was 21.3 years. They had an average of 1.2 children with seven of the participants (63%) having had no children. A majority of participants were single and had never been married (54.5%), while a small number were married (27.3%). A large percentage of the sample had some college education with 54.5% having some college, 9.1% having an Associate's degree, and 18.2% having a Master's degree. A majority of the men had paid employment (54.5%), while 45.5% were unemployed or receiving disability benefits. Except for one, all of the men had some type of health insurance coverage. Sports related injuries contributed to impairment for three of the participants (27.3%).

Variable	*M*	*SD*
Age	32.4	4.25
	n	
Marital Status		
Married	3	
Divorced	1	
Lives with significant other	1	
Never married/Single	6	
Highest Level of Education		
High school	2	
Some college	6	
Associate's degree	1	
Graduate degree	2	
Health Insurance Type		
No insurance	1	
Private pay insurance	2	
Private pay insurance through employer	3	
Medicaid	3	
MAP (Medical Access Program)*	1	
VA	1	
*The MAP program is funded by a separate political subdivision of the State of Texas. MAP provides access to health care for residents who meet enrollment criteria		
Annual Income		
Less than $10,000	2	
$10,000 - 19,999	4	
$30,000 - 39,999	2	
$50,000 - 59,999	2	
$70,000 or more	1	

Table 1: Sample Demographics

THE ESSENTIAL STRUCTURE OF HEALTH PROMOTION

One's body is ever present and interfacing with one's environment (Husserl, 1999), as such, it is constantly experiencing a variety of phenomenon. How one experiences a phenomenon is grounded in one's consciousness of it. Merleau-Ponty

(1962) asserts that perceptions of the body reflect an embodied consciousness of who we are in the world and what is perceived about the world around us, consequently, perceptions of the body may influence what is perceived by the mind. In disability, the body is required to renegotiate how it moves in the world, how it perceives its place in the world, and how it relates to the world (Merleau-Ponty).

What is perceived about the body is vulnerable to change in the context of disability. Merleau-Ponty (1962) asserts that our bodies want to experience the world in its best state and in the most efficient way possible. This becomes plausible when the body's needs are at the forefront of consciousness. Phenomenology requires a renewed consciousness of experience, resulting in a reconstruction of one's world based on past, current, and future embodied perceptions.

In discussing the essential structure, or essence of health promotion for this group of young adult African American men, it is imperative that one understands the philosophical basis of their experiences of health and health promotion. Furthermore, the author posits that understanding how these young men defined health is the first step in understanding their experience of health promotion. In an effort to gain an understanding of health from their perspective, the men were asked to provide insight into what health meant for them and whether or not they considered themselves to be healthy. For the men, health was multifaceted and its definition was shaped by their embodied experiences.

Like any other phenomenon, health is defined by the body and starts with what one believes and perceives about the body. Living with impairment gave the men in this study a uniquely embodied perspective of themselves, the world, and the meaning of health. As their bodies changed, the men's perception of their bodies also changed. In disability, their bodies' interaction with the world was often unfamiliar and daunting, thus they reported feelings of discord and disequilibrium when trying to adjust to living in a

changed body. This feeling of imbalance made it difficult for the men to adapt to living and thriving in a changed body and environment. They shared a sense of disconnect between the body and the self. The men found it particularly difficult to care for their bodies in the manner that they desired, thus a sense of balance or stability became the defining component of health for these men. The young men reported that health included being balanced across several domains: perceptions regarding the body/self, consciousness and reality, "healthy and unhealthy" behaviors, knowing about and doing for their bodies, and work and leisure. The men shared their belief that achieving health lead to a greater sense of purpose and clarity regarding who they were in the world.

Consciousness and reality are tied together through action (Merleau-Ponty, 1962). What one comes to know and understand about the body and the self, as well as the motivations and intentions underlying behaviors, occurs via the body when consciousness and reality meet and come to exist in the same embodied space (Merleau-Ponty). According to Merleau-Ponty, "To understand is to experience the harmony between what we aim at and what is given, between the intention and the performance--and the body is our anchorage in a world" (p. 167). While their description of health suggested that it was a state of equilibrium or balance that began with a renewed consciousness of the self, the men felt that health must involve action in order to be fully realized. Acknowledging the body's needs and responding in kind to those needs opened the door to the possibility of health promotion.

For these men, a renewed, or revived consciousness of the body and its needs formed the basis of health. Health involved an intentional focus on the self and what it needed to exist and thrive in the "life-world" (Husserl, 1999, p. 353). How then did these men define the essential structure and experience of health promotion? This section will present the findings for the following question: What is the essential structure of health promotion from the perspective of young adult African American men with mobility

impairment? The essential structure of health promotion was comprised of the following themes: *Reconciling Perspectives of the Self, Embracing the Current Body, and Reorienting the Body in the World*. The essential themes and their associated subthemes are presented in Table 1.

Themes	Subthemes
Reconciling Perspectives of the Self	• The Limited Body • The Confined Self • The Passive Body • Acknowledging an Altered Self
Embracing the Current Body	• Acknowledging the Body's Limitations • Pushing the Body's Limits • Preserving the Body • Appreciating the Body's Existence
Reorienting the Body in the World	• Refuting the Deficient Self • Consciousness of the Body's Needs • Acknowledging an Altered Self

Table 2: Essential Structure of Health Promotion Themes/Subthemes

Reconciling Perspectives of the Self

For these men, health promotion began with recognizing imbalances in the way they saw themselves. According to Stone (2005), learning to cope and adapt to a new way of life may make it difficult for the young man with invisible disability to reconcile the identities that he has ascribed to himself with those ascribed by society. The men of this study relayed that the world is experienced differently in the context of disability; however, a disability does not define nor does it diminish the inner self. The men had to decide what was true about how they saw the world and their existence in it.

For the young men in this study, one essential component of achieving health involved the need to establish and portray a true self grounded in their own embodied perspective. Incongruent perspectives of their bodies seemed to have influenced their place, being, and sense of purpose in the world where they felt challenged to decide which perception of their bodies would rule their consciousness. To progress toward a state of health, they needed to choose the perception that they felt would facilitate their existence in the world as well as act as the most valid representation of their core values, feelings, identity, and bodily potential. The subthemes associated with this theme were tied together based on their reflection of the various ways in which the men in this study perceived their bodies' existence in the world at different points during their journey to achieving health. Subthemes of this theme included *The Limited Body, The Confined Self, The Passive Body, and Acknowledging an Altered Self.*

The Limited Body

The men in this study felt that limits had been placed on their bodies' ability to function and exist freely. Even when injured, several participants voiced feeling like they had no choice but to limit or not allow their bodies the time and opportunity to rest and heal, resulting in feelings of dissatisfaction. For example, one participant mentioned feeling pressured to continue working despite significant injury and impairment. Even in experiencing chronic pain with activity, he felt that societal standards expected him to continue working in order to prove his ability to take care of himself and his family without the assistance of others:

> Yea and now, I cannot fail to work full time because how will I pay my mortgage, because you see these government help comes, but they have conditions. They will make you poor if you play around with them...So all that I'm thinking is that I have to be dependent...And walking is really a problem. I used to run. I was a good runner, but I cannot do that anymore. That standing really makes me feel bad. Standing and I cannot stand quickly like, so fast.

A young man with severe acromegaly and muscle weakness, spoke of the limits he felt were imposed on his body by health care institutions. He felt that his insurance status had influenced the health care he had received in the past, thereby limiting his health care options and treatments. He reported feeling like limits had been placed on the diagnostic tests his body was allowed to undergo simply because he was uninsured. This in turn limited his body's ability to get the resources it needed to assist it in healing itself. He shared his experience regarding an emergency room visit:

> First thing you do – you ask me – you go to any hospital, what insurance do you got? I've been to a hospital, I swear to you, I had the flu...They put another black dude but it wasn't racial but he worked for somebody 'cause he had his little work shirt on and stuff. They asked him what kinda insurance he had...I didn't have insurance at the time. They were like we're gonna get a stool sample, blood work, urinalysis from him. From me they said, well we just wrote you a prescription. Take this to one of the people's pharmacy or something over there or there are some charities that might help you get it filled. Good luck. They had me sit up there for eight hours just to hand me a slip of paper.

The Confined Self

The men shared feelings of frustration when discussing their bodies' inability to perform the mental and physical activities they used to do prior to their injuries. Their bodies' inability to do and be what it used to had altered their feelings of harmony with the world, as well as their perceived ability to overcome those obstacles. A young man who had suffered a back injury secondary to an "altercation" when he was 16-years old, described his experience with impairment as a "wound:"

> I got into an altercation with another individual and I never was the same after this incident. And..this is opening one of those wounds. I definitely try my best to work around things that might hinder me in being a productive member of society. For example, I can't walk a quarter mile without sitting down or at least, I have to hold onto something. I can't stand by myself because I'm a fall...It might not be like a muscle type of thing. It's gotta be in here (pointing to head). If I can find a way to help correct what's wrong, then I'm definitely going to aim for it and search for it. It can only make life better.

The participants often struggled to find ways to function and engage with the world within the confines of their physical and mental limitations. One man with a chronic back injury expressed his frustration with not being able to perform exercises at the same level he had once been able to. He described his feelings here:

> It makes me feel worthless, like what can you do? I can't even do pushups anymore. I can't do sit-ups anymore. Those are simple things. Those things come second nature. Running is second nature. But it still doesn't matter. If you used to do 50 and you dropped to five, it's crazy. It's like somebody who used to walk and they can't walk anymore. It's serious.

The Passive Body

The men described situations wherein they felt like a particular phenomenon, such as pain or age, outside of their control was manipulating and influencing their bodies' ability to function in the world. The men expressed feelings of vulnerability and powerlessness in trying to avert the changes happening to their bodies. One man spoke of his experience with his aging body:

> Somebody told me that after 25, it goes downhill, I laughed at him. I told him he lying. They haven't lied to me yet. After 25, that's when I had – a trigger all kinds of injuries for the past three years. I had shoulder issue that took me out of six months then I went into ankle issue that took me out for six months then went into back issue, that took me out for another three months and then my knee issue, the past year and a half. I haven't played full basketball in a year. Haven't played a full year for the past three years. So no more, no, it seems to be normal. After he hit 25, he went downhill.

Acknowledging an Altered Self

In an effort to move forward, the men expressed the need to look back and honor their former selves. The men reflected on who they believed themselves to have been at one point in their lives. In some ways, they felt a disconnect between their former and current selves because their bodies had undergone what they sometimes considered drastic, physical changes. How they interacted with the world had changed significantly,

in turn, they expressed a desire to adapt to their new bodies and be "normal" again. A man with a sports related injury described his experience here:

> ...It is a mental process. You talking about most of the time prepare hit the gym to get better, but I'm going to be hitting the gym just to get back to normal. That's something you just have to accept and hopefully just deal with it better.

A 32-year old former construction worker who ruptured a disk in his back after falling through a floor while working approximately eight years ago, shared his desire to function as he once did. He said, "I want to be able to walk around again. And at least be able to bend over and pick something up without having a hard time."

Embracing the Current Body

According to Sartre (1957), "there are no accidents in a life" (p. 54). He goes on to assert that every situation in life is shaped by one's choices and:

> since he is also the one who makes himself be, then whatever may be the situation in which he finds himself, the for-itself must wholly assume this situation with its peculiar coefficient of adversity, even though it be insupportable. He must assume the situation with the proud consciousness of being the author of it, for the very worst disadvantages or the worst threats which can endanger my person have meaning only in and through my project; and it is on the ground of the engagement which I am that they appear. It is therefore senseless to think of complaining since nothing foreign has decided what we feel, what we live, or what we are (p. 52-53).

In other words, this study's participants had the freedom to create their own values and viewpoints regarding their existence despite the opinions of others or current circumstances. Despite sharing painful experiences, the young men in this study considered the affirmation of their bodies' existence to be an important aspect of health promotion. There were several occasions wherein the participants expressed frustration, and sometimes anger, when discussing their bodies' limitations; however, they shared an underlying need to embrace the body-and subsequently the life-that belonged to them. In doing so, they accepted who they had been, who they now were, and who they had the

potential to become. Accepting their current bodies influenced their belief in their potential for health thereby encouraging a belief in their bodies' need to be protected and preserved through healthy habits.

Even with its limitations, the men felt an appreciation for the state of being of their current bodies. In developing an appreciation for the existence of their bodies, the men seemed to go through a process of first recognizing their body's limitations which served to heighten their awareness of the narrative they ascribed to their bodies. The participants shared instances where they described going beyond the limitations of their bodies. Pushing beyond their bodies' limits seemed to be an avenue for proving their bodies' capabilities. Further, there seemed to be a glimmer of hope that their body would respond to that push and somehow begin to function beyond the boundaries of its limitations. In pushing their bodies, the men often realized that they were doing their bodies more harm than good and they needed to protect and preserve their bodies in order to facilitate long term health. In order to care for their bodies, the men discussed the need to assign an inherent value to it simply because it belonged to them and made their existence in the world possible. Associated subthemes of this essential theme were: *Acknowledging the Body's Limitations, Pushing the Body's Limits, Preserving the Body, and Appreciating the Body's Existence.*

Acknowledging the Body's Limitations

Although not always wanting to, participants admitted that their body's limitations were a reality of their state of being. The renewed consciousness of their limitations served as an acknowledgement of their bodies' inability to consistently perform in the manner they desired. It also served as a reminder of their bodies' fragility and vulnerability as well as a recognition of their current presence in life and need to figure out how to live in a changed body. One participant described his experience:

> Once when I run – when I am – when I keep on running I do a lot of – my other things very swiftly. I feel light. My body feels light. My body feels flexible. My body feels the small challenges, they are easy to do...I miss that feeling of – the flexibility of my body and feeling like I'm light...Yes, I do exercise, I go out to the gym, I lift weights and yea. I do exercise, yea – I'm able, but limited based on that situation now. Not as much as I used to do.

Pushing the Body's Limits

A participant, who had experienced chronic weakness and pain secondary to being shot several times, said that every day for the African American male with an invisible disability is "like a trial" implying that each day brings with it a number of physical and mental challenges. In an attempt to overcome these challenges, the men described regularly pushing their bodies beyond its proven physical capabilities, often resulting in further pain and injury. The men seemed to have a need to try and balance their aspirations for their body with its current existence. An Army veteran with a shoulder and back injury described his experience with attempting to run despite debilitating back pain:

> Woke up this morning, get up, put my clothes on, and I said, "I'm going to run." So I started running and ran from here all the way down. I reached down there and my back started killing me. I said, "Okay, that's it. I'm done." I turned back and came in and laid on the floor for three hours. I couldn't move. My back was killing me. I was like, "Wow. Why the hell did I decide to run?" I want to lose weight. I was like, "Man, I need to lose weight. I'm going to run through this pain." My doctor told me I need to exercise more. I need to play sports and stuff like that. Don't injure your back, but still do stuff and do it to the limit. And when you reach that limit, you stop. But damn that limit hurts.

Preserving the Body

This subtheme addresses the act of protecting one's body and thereby ensuring its continued existence in the world. Several participants shared instances wherein they felt an almost instinctual need to protect their bodies from being harmed by another person and very often from their own unhealthy habits and behaviors. When asked to describe a time when he had to protect his body, one gentleman said:

> I said I'm allergic to penicillin. They said what are the side effects of you taking penicillin? I said death. I said you'll have little x's on my eyes like a cartoon. Me, the doctor and the nurse laughed. Guess what he put down on my prescription, when the pharmacist said, I see here Mr. ____, you're allergic to penicillin, and he prescribed you amoxicillin. I'm like he doesn't know that's in the Cillin family? That's penicillin. He's like no, I wasn't gonna give you that. I'm like I would have caught it too, but thank you a lot. I'm not one of those people that just takes something. I'm not that ignorant.

Another participant shared a similar experience:

> I was told that I had high blood pressure and they wanted to put me on this medicine that was called Atenolol. They wanted me to take. And I was like no way. I'm not doing it... I think one of the biggest parts for me not taking the medication is because I already have a low heart rate already. It's been like that my whole life. And so, Atenolol takes and it lowers, it drops that rate and so it was like I'm already low as it is so why am I going to take and take that that's gonna drop my (heart rate)..and so that was a big reason why I didn't do it.

Appreciating the Body's Existence

In an effort to move in the direction of improved health and doing the things necessary to care for their bodies, participants felt that they had to first appreciate the existence of their bodies. In essence, they each had been challenged to appreciate the current state of their bodies and its presence in the current place and time. Several of the men expressed this appreciation to God or a "higher power," suggesting that their bodies existed only because God had allowed it to. One gentleman shared his insight:

> Yeah, I am disabled technically. But that's life to me. That's how it is. I'm used to having a headache. I'm used to being tired. I'm used to feeling sleepy. I'm used to – I just tell myself instead of thinking on little things like that I just say, thank God I'm alive. Thank God I'm not in a hospital bed. With IVs in my arm like my aunt is or like those people in the hospital are, I can move still. As long as I can people will be – every night I go on my knees and I say my prayers.

Reorienting the Body in the World

According to Merleau-Ponty (1962), we discover and interact with the world through our bodies; therefore, the body is the starting point for orienting oneself in the world (Husserl, 1995). When the body is changed in disability, it stands to reason that

how one interacts with the world is also changed. Gibson, Placek, Lane, Brohimer, and Lovelace (2005) discovered this "loss of self-positioning" in their study of persons with multiple chemical sensitivity (p. 509). An altered body spurs a renewed consciousness of the body and what it needs to function and achieve health. In the context of the impaired body, the men recognized the evolvement and importance of their body's needs, thus inspiring the desire to balance their embodied existence in the world. The young men in this study shared stories wherein they had struggled to reestablish their position in a world that oftentimes felt overwhelming; however, the men did not consider their bodies deficient or irretrievably broken, but certainly different than before. For them, an essential component of health promotion involved the reestablishment and reorganization of their bodies in the world while adjusting to living with invisible disability. This theme built on the following subthemes: *Refuting the Deficient Self, Consciousness of the Body's Needs, and Acknowledging an Altered Self.*

Refuting the Deficient Self

There were several instances when participants described some incongruence between how they viewed their bodies and how they felt their bodies were viewed by others. Merleau-Ponty (1962) describes the body as, "a form, that is to say a phenomenon in which the totality takes precedence over the parts" (p. 114). Despite having an invisible disability, the men still felt that their bodies were capable and had the potential to one day improve its level of functioning. In addition, because they were still able to fulfill some life roles, they did not always consider themselves to be completely "disabled," even though societal standards may have said they were. One young man shared his insight:

> Not really, when I think about disabled, I think about people in a wheelchair, for some reason. But I do got a cane that I walk with sometimes when my back start getting bad. I got a back brace. But still, I think about people that's in a wheelchair. Or one of their legs have been cut off, stuff like that. I try not to

> think of myself as being disabled. Even though the paperwork say I am. And the research say I am. But I try not to think about it in that text. Because my picture of someone disabled is somebody in a wheelchair.

When asked why he did not consider himself disabled when he was clearly unable to control his body in the way that he desired, the same participant responded in the following manner:

> If I put myself in that category I'm going to start living that life. But I don't want to live that life. I'm too young to be living the disabled life. It's all about your mind. If you think you're poor, you'll always be poor. If you think you're rich, one day – trust me, even if you ain't got money you have a rich mindset. So it's all about your thoughts about yourself. The mind is very powerful. If I think I'm disabled, my body will start automatically getting worse. If I think I'm not, if I think I might get better one day, I must get better one day, then I know it's more beneficial to me to have that thought in my head. If I think I'm disabled I'll be more depressed than I already am.

Consciousness of the Body's Needs

While expressing a belief in more than one domain of health (e.g. mental or physical health), the men in this study spoke of a burgeoning consciousness of what they felt their bodies needed in order to garner or maintain health. The men readily admitted to being aware of what activities and behaviors would benefit their bodies; however, they readily disclosed that they did not always do what they believed they should. One participant shared the following insight:

> It influences a lot because I realize now that I have to start taking care of myself because if I don't, then I'm going to, like, end up with cancer and diabetes and prostate cancer, colon cancer if I eat too much red meat. Diabetes if I eat too much sugar and starch. You know, cancer if I smoke too many cigarettes. I mean, it's just like you have to realize that, you know, you could be worse off or you could be better off depending on your choices so I try to not use too much sodium, not use too much starch, not eat too much red meat.

Acknowledging an Altered Self

The men had experienced significant changes to their bodies; therefore, who they were in the world and how they interacted with the world had changed considerably.

After impairment, they readily admitted that they were no longer, and could no longer be, the men they once were. To experience health, they had to relinquish old ideals and values while embracing a conjoined perception of their past, current, and future selves. A young man who had been an accomplished collegiate athlete shared his experience:

> For instance if I bend over and tie my shoes I have to gasp for air...Every day I woke up ready to exercise when I was a track athlete, you know in college. I would do like hundreds of pushups and hundreds of sit-ups, crunches or whatever. I was like that motivated...So it was like, you know just not having that type of drive anymore, you know what I'm saying – to wanna stay fit and always know like, man, I'm scared to do this because my back might start hurting if I do it. Then I start feeding myself more and more excuses and I start accepting those excuses...So that's when I was, like I said, the happiest, you know within myself health wise.

When asked to discuss his feelings about who he was before and after impairment, one young man responded:

> That was yesterday, and I can't live in yesterday because I'll get stuck in yesterday. I think about the future and what kind of future will I have for myself. Things I do today determines my future tomorrow.

THE LIVED EXPERIENCE OF HEALTH PROMOTION

The lived experience of the body is grounded in the principle that any ascribed meaning of an experience is inherently embodied (Merleau-Ponty, 1962). Merleau-Ponty also asserts:

> Tomorrow, with more experience and insight, I shall possibly understand it (my past) differently, and consequently reconstruct my past in a different way. In any case, I shall go on to interpret my present interpretations in their turn, revealing their latent content and, in order finally to assess their truth-value, I shall need to keep these discoveries in mind (p. 403-404).

In disability, the body has been manipulated and cannot be reconstructed, but the mind can be. An individual is unable to change the past, but is able to recreate its meaning in the present. In recollecting and reflecting on past experiences, the men in this study found themselves revisiting the notion of allowing their bodies the freedom to become exactly

what they needed it to be in any given situation and at any given time. For the men in this study, the essential structure of health promotion was the quest for wholeness and a unified horizon of their past, present, and future selves.

Participants expressed a desire to see themselves anew and broaden their current perceptions of themselves, but felt the process was fraught with possible risks to their bodies. During their journey to achieving health, the men found themselves using and risking their bodies to renegotiate and revise perceptions of their bodies and their environment. The young men wanted to function and thrive in the world within a space of empowerment, strength, pride, and hope. Their health promotion experience required putting the needs of the self before the needs of the body and then accepting and valuing the resulting condition of the body. The men reported fearing the unknown, but felt that the risks were worth it if it afforded the opportunity of attaining a substantiated sense of self, fulfillment, and, "cultural validation" (Thomson, 1997, p.80).

This section will present the subthemes and themes used to convey the lived experience and ascribed meaning of health promotion for a group of young adult African American men with invisible disability. The following themes were identified: *Risking the Body to Preserve the Self, Accepting the Evolving Body, and Seeking the Body's Redemption*. The themes and their associated subthemes are presented in Table 2.

Themes	Subthemes
Risking the Body to Preserve the Self	• Pushing the Body's Limits • Perceiving an Alternative Self • Inaccurate Narrative of the Body • Suppressing the Authentic Expression of Self
Accepting the Evolving Body	• The Unfamiliar Existence of the Body • Refuting the Deficient Self • Appreciating the Body's Existence • The Changed Body
Seeking the Body's Redemption	• Consciousness of the Body's Needs • I am Still a Man • Intentional Surrender of the Body

Table 3: The Lived Experience of Health Promotion Themes/Subthemes

Risking the Body to Preserve the Self

"The body is our general medium for having a world. Sometimes it is restricted to the actions necessary for the conservation of life, and accordingly it posits around us a biological world" (Merleau-Ponty, 1962, p. 169). The body is central in shaping experiences, perspectives, and actions. The young men in this study reported taking risks that had been influenced by the ways they felt about their body's existence and potential. Despite impairment, participants shared a common belief that their bodies still had the potential to achieve health. They shared that they would often push their bodies beyond its limits in an effort to make their bodies conform to their expectations. In doing so, they would often put their bodies at risk for further injury.

In becoming conscious of their bodies' needs, the achievement of health became plausible for the men in this study and they were willing to risk their bodies by seeking health care. Based on past interactions with health care entities or a belief in their own invincibility, some participants felt that their bodies were "safest" or the least vulnerable

outside of the health care realm-although they also admitted to knowingly harming their bodies with what they considered unhealthy habits. From the men's perspective, unhealthy habits included pushing the limits of their bodies, chronic cigarette and marijuana smoking, eating foods with high fat content, and sexual intercourse outside of marriage. The men reported that engaging in unhealthy habits often helped them "cope with the stressors of daily life. One participant described cigarette smoking as, "Like a hand in glove – a way to escape, oral fixation, just stress management." Some participants expressed no intention of giving up habits they considered unhealthy, while others expressed a desire to one day do so.

The men felt that health care providers could not relate to nor did they understand their embodied experience; therefore, they considered their bodies to be at greatest risk while under their care. The men were charged with making the decision to remain vulnerable only to themselves, or to become vulnerable to health care providers as well. In either case, there was the potential of risking further "damage" to the body and the self. This theme built on the following five subthemes: *Pushing the Body's Limits, Perceiving an Alternative Self, Inaccurate Narrative of the Body, and Suppressing the Authentic Expression of Self.*

Pushing the Body's Limits

Every participant involved in this study reported pushing their bodies beyond points of injury or pain in an effort to perform at an expected level. Harrison (2005) described this same phenomenon in her study of women aging with childhood onset paralytic polio. Like the young men in this study, participants in Harrison's study often pushed their bodies to do activities that seemed to exacerbate existing physical and emotional stressors causing further physical decline. A man with a chronic back injury admitted to neglecting his initial injury:

> Well I was working out one day is when I really noticed it. I was doing, we was doing these pushups and we had to get up and do some jumping jacks and I kept feeling this sharp pain...I went and I seen the doctor a couple of times. They told me what was going on, I neglected it to tell you the truth. I kept on working. I got a moving job and..yeah. Aw yeah, I was determined that I was going to beat this. I'm young and I can do this and I didn't want to hear anything.

The reasons for pushing their bodies were varied, but were commonly associated with the desire to do "what men are supposed to do." One participant's explanation mirrored the sentiment of the group:

> As a man growing up, if you grew up the right way and the right principal of being a man, you know a man takes care of his house. A man takes care of his family. A man takes care of himself. And a man gets things done. If you're in a situation where you can't do any of that, you feel less of a man. It's not because somebody makes you feel that way, but because your condition makes you feel that way. It's depressing given that you're a driven person. You're very ambitious and you're dependable.

Perceiving an Alternative Self

It is impossible to experience the body of another (Merleau-Ponty, 1962), so one is likely to depend on the outward appearance of a body to determine what one will perceive about that body. It is during this attempt at defining the body, that inaccurate assumptions are likely to arise. According to Stone (2005), living with an invisible disability is often associated with shame and stigma due to the ways in which a person internalizes the ways he is treated or regarded by others.

The young men felt that their perception of themselves was influenced by not only their own experiences, but was also impacted by the way others had perceived their bodies. Several participants voiced that they often perceived a different or alternative self than the one they felt had been assigned to them. The opinions of others appeared to have implications for how the men experienced and felt about their bodies. In other words, they experienced their bodies differently based on the feedback they received from others regarding their bodies. The ability to reconcile or discount incongruent narratives about

their bodies was considered beneficial for promoting a belief in their bodies' potential for health. One participant offered insight into his experience:

> I don't really think that it's me per se it's the perceptions and the bullshit that people are allowing to be brought into their perception of reality. So that's why I say I'm not mentally well because I'm purposely on the outside of what is socially acceptable in the social norm. So if I'm the outcast then I have to be deemed as something wrong with me. Because there's nothing wrong with all of them. They all doing the same thing...But society deems me the wrong person. I'm the bad one.

Inaccurate Narrative of the Body

According to Thomson (2000), "The disabled body demands a narrative" (p. 334). It was not uncommon for several men in this study to share instances where they felt that what they felt to be true about their bodies typically differed greatly from the opinions and feelings of other people. The men would describe instances wherein their embodied experience of being made them believe certain things about their bodies, while being told by others that what they believed was untrue. In some instances, the men discovered or substantiated the personal narratives they held of their own bodies based on the narratives assigned to them by others. One young man shared this experience describing his initial back and shoulder injury:

> They thought I was fakin' even up 'til I took my MRI. It came back that my back is messed up. And they seen it. They still think I was fakin'. It made me feel like the military don't really give a damn about you. You're only good to them when you're 100 percent. But once the percentage started falling off they started shutting you off and pushing you away, no matter how much good you've done or how many medals you've collected. Once you get hurt, because they're not hurt they think you're bullshitting.

Suppressing the Authentic Expression of Self

The participants in this study expressed a belief that what others felt about their bodies had implications for how they felt about their bodies. In other words, they were likely to experience their bodies differently in the presence of another. The feedback and

responses of other people seemed to color their embodied perception of who they were; therefore, the self that they chose to present to others was impacted. The men reported often finding themselves trying to portray someone they were not. One man described an instance where he felt like he had to portray society's idea of what being disabled looked like. He reported feeling pressured to refill pain medication prescriptions that he felt were ineffective in order to secure permanent disability benefits although he felt that he had made significant progress both mentally and physically:

> They put you in a sticky situation. You have to refill. I'm on a temporary disability. In order for me to go on permanent, I have to do all this dumb crap. They know my back isn't getting better... Nobody ever gets cured for PTSD. But still, they want to put you on this temporary thing and you come back to them and they ask you, "Are you adjusting?" "Yeah, I'm adjusting good." "Okay, we'll cut your benefits." What? You think if I tell you I'm adjusting to life, you'll cut my benefits? You think that's going to make me better? That'll make me worse.

Accepting the Evolving Body

How one perceives the capabilities of their body provides the basis of how one views their body's health potential (Kelley-Moore, Schumacher, Kahana, & Kahana, 2006). Toombs (1995) purports that for persons with disabilities, "The sheer physical demands of impaired embodiment ground one in the present moment, requiring a disproportionate attention to the *here* and *now*. One is forced to concentrate on the present moment and the present activity rather than focusing on the next moment" (p. 19). In accepting their changed and changing bodies, the men of this study recognized the connection to their past selves through their minds i.e. thoughts, perceptions, and emotions. They worked hard to appreciate and accept the fluid nature of their existence.

> It can now be said that, a fortiori, the specific past, which our body is, can be recaptured and taken up by an individual life only because that life has never transcended it, but secretly nourishes it, devoting thereto part of its strength, because its present is still that past (Merleau-Ponty, 1962, p. 98).

The ongoing exchange between the young men, their bodies, and the world, reflected fluctuating perceptions of their bodies. In accepting their changing bodies, the young men were accepting their evolving identity and existence in an ever-changing world. This theme was based on the following subthemes: *The Unfamiliar Existence of the Body, Refuting the Deficient Self, Appreciating the Body's Existence, and The Changed Body.*

The Unfamiliar Existence of the Body

A young man who had injured his back and shoulder while working, voiced that he often felt that no one really understood his situation. He expressed doubt that he would ever return to his previous level of functioning and way of life, "And that's what people don't understand. People think you can go back. You cannot go back. You will never go back." He, like the other men in this study, shared that his body sometimes felt foreign, almost as if it did not belong to him. The men experienced the world through their bodies, but their conscious connection to their bodies was weakened in disability; however, in recognizing the unfamiliarity of their bodies, the men were often inspired to grow or change in some way in an effort to regain some familiarity with their bodies. A participant with chronic obesity shared his experience:

> Realistically, I didn't know I weighed that much. I didn't really think I weighed that much. I know I'm big. I got weighed at really quick weight loss. Because they have a scale over there and I went over there and got weighed and went "Oh my, oh no." Let me try this again. Okay. Let me take my shoes off. I think that added a pound. I said "Okay, this is really the devil."

Refuting the Deficient Self

After acquiring an invisible disability, the men in this study reported being challenged to sort out their own embodied existence and decide how they would regard their bodies. According to Merleau-Ponty (1962), "What it is in us which refuses mutilation and disablement is an *I* committed to a certain physical and inter-human world, who continues to tend towards his world despite handicaps and amputations and

who, to this extent, does not recognize them *de jure*" (p. 94). Participants shared feeling like society expected them to consider themselves inherently deficient with a limited capacity to achieve because their bodies had been impaired. The men did not accept this assessment and instead chose to focus on their bodies' capacity instead of its limits, thereby opening their horizons to the possibility of health promotion. A young man shared his insight:

> So I definitely give it my all regardless of being disabled or not feeling like a complete human being. You know sometimes those thoughts do occur while I'm traveling through the day. Hey, I'm not like normal people. I can't do these things like normal people, but I do not let it affect me because hey I might be weaker in this area of the field, but I might be stronger in the other area. See, so the other area is what I'm focusing on.

Appreciating the Body's Existence

Despite impairment and limitations, the men expressed an appreciation for their bodies' existence in the world. The men were able to ascribe inherent value to their bodies because their bodies allowed them to be present in the world. The men realized that in appreciating the existence of their bodies, they were opening themselves up to new possibilities regarding their futures. One gentleman offered insight into his experience:

> You have to just-it's a gift that you have to cherish. Does everybody cherish it? No. It took me 30 some years to start cherishing it. But it took some circumstances in between that from the age of 12 on up to get to where I was. It's just a gift that you have to take care of because it can easily be taken from you. If you mistreat it, it will shut down on you in a minute. But everything's a gift you have to cherish it. You can abuse it. Like I have so far but thank God I didn't abused it too much to where it has hindered me.

The Changed Body

Phenomena such as age and impairment can cause significant changes to the body. The men acknowledged that their bodies had changed and were unlikely to return to their previous state of functioning and being. Some bodily changes inevitably occur with aging; however, some changes are shaped by personal choices. One participant

recognized changes in his body's ability to perform and admitted that he may have contributed to those changes:

> Maybe the only thing is that I've put more pounding on my body and now my body at this point, she doesn't forget things...I never saw it broken until I started getting hurt and it took me longer to come back. And you start doing analysis; dive in a little bit deeper, looking left and right, but it's really hard to that because I never felt like I needed to.

Seeking the Body's Redemption

For these young men, their bodies were simultaneous reflections of their vulnerability, potential, and intrinsic humanity. The men felt that their injured or damaged bodies had been "discarded" by society, and in some cases by the young men themselves; however, they also forgave their bodies' limitations and inability to be "normal," and felt that their bodies deserved to be reclaimed-similar to the way in which a favorite pair of shoes is put back in the closet after being slated for donation. The men desired to free their bodies from the negative stigma of disability and allow it to move into its potential.

As the men recognized and understood their body's potential, they were motivated to maintain what they believed to be God's gift of the body. They felt that seeking God and His will in their lives would validate their current existence in the world, as well as their right to experience health. In their quest for a more intimate relationship with their God, they reported a desire and need to relinquish control over their lives and allow God to cultivate hopeful purpose in the context of the body with disability. Reconnecting with God served as a means for reconnecting with and understanding themselves, while honoring the gift of their bodies and selves. This theme built on the following subthemes: *Acknowledging the Body's Limitations, I Am Still a Man, and Intentional Surrender of the Body.*

Acknowledging the Body's Limitations

Acknowledging the boundaries of the body required a certain amount of humility on the part of the young men of this study. Though sometimes reluctant to do so, they had to acknowledge the limitations of their bodies in order to learn how to reconstruct their existence in those changed bodies. Furthermore, owning up to their limitations served as the impetus for securing resources and services they felt were integral to them achieving health. One participant described his ordeal of trying to secure the disability benefits he felt that he needed. Although he considered himself both mentally and physically disabled, he had been denied disability benefits several times.

> Just because my leg didn't get cut off, or I don't have three of my fingers missing, that, hey, you're gonna be okay. Like there's nothing wrong with you. You can pretty much heal from everything that just happened. Well, mentally, you can't heal. You'll be forever tarnished. That stuff reoccurs in my head. Not so much as did in the past years, but I still think about all that that happened, and the stress and anxiety that comes with it. That too plays a mental – it's damnation to your health because it kinda makes it seem like it was your fault.

I Am Still a Man

Socially imposed disability denies an aspect of the individual, but not the total person (Husserl, 1995). The men's belief that their manhood remained unchanged, challenged the socially accepted ideals of masculinity related to physical prowess (Courtenay, 2000). The young men did not want their collective identities to be defined only by their impairment and struggled to exist outside of its imposed societal confines. Despite having invisible disability, the men in this study appeared to be urging health care providers to value the totality of their embodied existence not only in the health care arena, but also in the world itself. They felt that in doing so, providers would recognize and value the shared humanity between them. The men wanted health care providers to look beyond themselves and facilitate interactions reflecting a shared horizon grounded in acceptance, intimacy, and respect. When asked what advice he had for health care

providers wanting to provide effective care to African American men with disabilities, one participant said:

> It was kinda designed for them with them in mind, with the – making that kinda attractive to them. Make it a comfort zone. Make it to where they can come there and it's not like they in a – just like a clinical hospital. Make it to where it's kinda like you know them by name, you know? You see them. They come in. You make them feel like, you know, they're at home. And one-on-one – explaining it to them one-on-one, actually getting to know them and what they do.

Intentional Surrender of the Body

Husserl (1999) asked the question, "Shall we say that God sees the things as they are in themselves while we them through our sense organs, which are kind of distorting eyeglasses?" (p. 172). In wanting to be perceived as inherently valuable by themselves and others, the men reported a burgeoning consciousness of God's enduring presence in their lives. As the young men recalled the things that God had done for them and their families in the past, they were inspired to strengthen their relationship with Him. They yearned to make the relationships with God and themselves the highest priorities in their lives. They shared a desire to experience their God differently than they had in the past and expressed a sincere desire to surrender control of their lives to an entity who they felt could assist them in achieving a meaningful existence. McColl and her associates (2000) discovered these same phenomenon in their study of spirituality among persons with disabilities.

The men often struggled with feelings of self-loathing and frustration related to their difficulty in accomplishing the life goals and standard of living that they, their families, and God had deemed appropriate. One young man felt that God was the only one capable of helping him create a sense of harmony within himself and maintain control of his thoughts and actions. He spoke of having free will, but acknowledged that it had not brought him closer to God. He shared this:

> Because that's the difference between humans and angels. We have free will. They don't. You know, once you see God, you have no choice but to love Him unconditionally because you realize that He's real. Like I said last time, I am trying to get closer to him because I don't always do the right things. I don't control my body and I give into lustful things.

CHAPTER SUMMARY

Hermeneutic phenomenology contextualizes the experience of a phenomenon; therefore it was used in this study to uncover the essential structure and lived experience of health promotion for a sample of young adult African American men with invisible disability. As evidenced by the stories of this study's participants, the meaning of health and health promotion is shaped by multiple perspectives and experiences.

Perceptions are embodied or situated within the context of the body; therefore, as the body changes, perceptions of the world change as well. For the men in this study, health was a reflection of their embodied existence in a world they were learning to adapt to. For the men, learning to navigate the world while living with disability, often resulted in feelings of dissonance and imbalance. These perceptions of imbalance made it difficult for the men to care for their bodies in the manner that they desired, thus a sense of balance or stability became the defining component of health. The young men desired balance among their perspectives, health habits, activities, and responsibilities. Their belief in their ability to attain and maintain health, made health promotion plausible.

Disability does not completely define the self, but is does shape one's interaction with the world. The young men in this study found themselves having to decide who they were going to be in the world. They were challenged to define themselves based on their own perceptions as well as feedback from others. Their definitions of themselves had implications for how they felt about their bodies. Having developed a renewed consciousness of their bodies, the men recognized their bodies' limitations and sometimes pushed their bodies beyond those limitations in order to authenticate perceived

capabilities. Despite limitations, the men recognized that their bodies made their existence in the world possible; therefore, they felt that it deserved to be protected and valued. Affirming the existence of their bodies became an integral aspect of health promotion.

As the body changes, an individual is challenged to develop a consciousness of how the needs of the body have changed. What the body needs to function and achieve health is altered in the context of the body with invisible impairment. In recognizing and navigating those changes, the men struggled to reestablish their position in a world that oftentimes felt daunting. For them, an essential component of health promotion involved the reestablishment and reorganization of their bodies in the world while adjusting to living with disability. For these young men, the essence of health promotion was comprised of the following themes: *Reconciling Perspectives of the Self, Embracing the Current Body, and Reorienting the Body in the World*.

The lived experience of health promotion for this group of young adult African American men was fraught with possible risks to their bodies. In their attempts to revise perceptions of their bodies and their environment, the men often risked their bodies. These risks were shaped by the men's perceptions of themselves, past experiences, their health potential, and their environment. Their health promotion experience required putting the needs of the self before the needs of the body and then accepting and valuing the resulting condition of the body. Furthermore, health promotion involved accepting their changed bodies, as well as the fluid nature of their existence (Husserl, 1999) thereby aiding them in adjusting to life with disability. The men reported looking to God to validate their bodies' existence and potential for health. The lived experience of health promotion was reflected in the following themes: *Risking the Body to Preserve the Self, Accepting the Evolving Body, and Seeking the Body's Redemption*.

Chapter 5: Summary, Conclusions, and Recommendations

INTRODUCTION

The purpose of this chapter is to summarize this research and to provide recommendations for future research. The majority of this chapter is devoted to a summary and discussion of the meaning and significance of this study's findings against the background of current literature. The second part of this chapter will discuss the investigator's conclusions, implications for nursing practice, as well as recommendations for future research.

SUMMARY OF THE STUDY

The disablement experience (Verbrugge & Jette, 1994) is shaped by individual behaviors as well as by societal factors such as the availability of disability related services that facilitate functioning. Understanding the health promotion experience provides insight into the health related factors that may impact the progression from impairment to disability. The concept of health-within-illness (Lindsey, 1996; Moch, 1998) draws an intimate connection between the experiences of health and invisible disability. Literature suggests that the concept of health-within-illness is plausible for people with disabilities and chronic disabling conditions; therefore, it and the philosophical framework of hermeneutic phenomenology served as the basis for exploring the health promotion experience of young adult African American men with non-visible impairment.

Disability is associated with a number of social determinants of health including lower employment rates (Iezzoni, 2009), and limited access to quality health care (Tomlinson et al., 2009). Furthermore, persons with disabilities typically experience poorer health outcomes than persons without disabilities and are at greater risk of developing secondary conditions associated with chronic disability (Dejong et al., 2002;

Harrison, 2006; Iezzoni, 2009). Living with an invisible disability adds its own unique challenges to promoting one's health. Persons with invisible disabilities often suffer with feelings of stigma (Boyles, Bailey, & Mossey, 2011) and isolation (Davis, 2005). These feelings may impact how they feel about their bodies and their potential for attaining health.

For African American men both with and without disabilities, long-term health can be difficult to achieve and maintain. African American men without disabilities experience the highest incidence and mortality rates for all cancers and are more likely to contract and die from HIV/AIDS than non-Hispanic white men. In addition, they experience a 40% higher incidence of diabetes mellitus, type 2 than non-Hispanic white men (U.S. Department of Health and Services, Office of Minority Health, 2007). Among African American men, those with disabilities experience higher rates of morbidities and mortality than African American men without disabilities (Centers for Disease Control, 2010; Iezzoni; Krahn et al., 2006).

There is a paucity of literature exploring the underlying factors and health related experiences at earlier life stages of African American men with invisible disability that may contribute to the development of health problems over time. Understanding the health promotion experience of this group within the context of their "life-world" (Husserl, 1999, p. 353) may provide valuable guidance for health care providers and researchers designing health promoting interventions targeting this population. This study answered the following research questions:

1. What is the essential structure of health promotion from the perspective of young adult African American men with invisible disability?
2. What is the lived experience of health promotion for young adult African American men with invisible disability?

Hermeneutic phenomenology allowed for a contextualized understanding of health promotion for a sample of young adult African American men with mobility impairment. Hermeneutic phenomenology allowed the investigator to assume that the health promotion experience of young adult African American men was shaped by their embodied life circumstances and was therefore a unique experience. Exploring health promotion from the perspective of young adult African American men with invisible mobility impairment provided the opportunity to discover comprehensive insight into their unique experiences. Hermeneutic phenomenology guided the data collection, data analysis, and presentation of findings (Cohen, Kahn, & Steeves, 2000) for this study.

This study used a non-experimental, descriptive design and its participants were recruited using a variety of methods which included contacting community liaisons and visiting local churches with large numbers of African American parishioners. The purposive sample consisted of 11 young adult, English-speaking, non-institutionalized, African American men with invisible disability between the ages of 25 and 39 years of age living in the Central Texas metropolitan area. Young adult African American men who had no known cognitive impairments severe enough to significantly impede their ability to participate in the interviews were included in this study. Participants must have reported mobility impairment of at least six months duration. To be eligible, participants must have reported difficulty or inability to perform 2 out of 4 functional limitations identified in the National Health Interview Survey (2010): (a) walk a quarter of a mile, (b) walk up 10 steps without resting, (c) stand for 2 hours, or (d) stoop, bend, or kneel (U.S. Department of Health and Human Services, 2010). Efforts were made to select participants who represented varying backgrounds and a broad range of disability experiences (e.g. age at onset/occurrence of impairment, pathology type, and socioeconomic status).

This study's research questions were answered using audio-taped, one-on-one qualitative interviews along with detailed fieldnotes. Participants were interviewed twice at a mutually decided upon location to ensure the privacy and comfort of participants. Interviews often took place either in their homes or at the University's school of nursing. The young men were asked a variety of questions designed to elicit responses pertaining to their lived experience of health promotion (Please see Appendix A). Qualitative datum was analyzed using the process outlined by Cohen, Kahn, and Steeves (2000). The planned data analysis steps were organized into six steps: preliminary interpretation of interview data, data immersion, data reduction, line-by-line coding, grouping of unit meanings into categories, and grouping of categories into themes. Demographic data was entered into SPSS 20.0 for statistical analysis. Descriptive statistics were used to summarize the demographic makeup of the sample.

Findings

The findings of this study are indicative of how complex the experience of health promotion can be for an individual. According to Husserl (1999), a person is what they imagine themselves to be and the perception of one's body is constantly evolving. Perceptions of the body and its potential for health are likely to be based on both personal and interpersonal dialogues. One's perceptions are embodied or situated within the context of the body; therefore, as the body changes, perceptions of the world also change. For this group of young adult African American men with invisible disability, health involved a renewed consciousness of the body and its needs and was a reflection of their balanced existence in a changed world. For the men, learning to navigate the world while living with disability often resulted in feelings of dissonance and imbalance. These perceptions of imbalance made it difficult for the men to care for their bodies in the manner that they desired, thus a sense of balance became the defining component of

health. The young men desired balance among their perspectives, health knowledge, health habits, activities, and responsibilities. Their belief in their ability to attain and maintain health, made health promotion plausible.

The Essential Structure of Health Promotion

The state of the body shapes how one interacts with the world. The young men in this study found themselves having to decide who they were going to be in the world. They used feedback from themselves and others to ascribe meaning to their bodies. How they defined themselves had implications for how they viewed and treated their bodies. Having developed a renewed consciousness of their bodies, the men became aware of their bodies' limitations and sometimes pushed their bodies beyond those limitations in order to authenticate perceived abilities. Despite limitations, the men recognized that their bodies made their existence in the world possible; therefore, they felt that it deserved to be protected and valued. Affirming the existence of their bodies became an integral aspect of health promotion.

As the body changes, an individual is challenged to become conscious of how the needs of the body have changed. What the body needs to function and achieve health is altered in the context of the body with invisible impairment. In recognizing and navigating those changes, the men struggled to reestablish their position in a world that oftentimes felt daunting. For them, an essential component of health promotion involved the reestablishment and reorganization of their bodies in the world while adjusting to living with disability. For these young men, the essence of health promotion was comprised of the following themes: *Reconciling Perspectives of the Self, Embracing the Current Body, and Reorienting the Body in the World*.

The Lived Experience of Health Promotion

The lived experience of health promotion for this group of young adult African American men was fraught with possible risks to their bodies. In their attempts to revise or validate perceptions of their bodies and their environment, the men often risked their bodies. These risks were shaped by the perceptions the men had of themselves, their past experiences, their health potential, and their environment. Their health promotion experience required putting the needs of the self before the needs of the body and then accepting and valuing the resulting condition of the body. Furthermore, health promotion involved accepting their changed bodies, as well as the fluid nature of their existence (Husserl, 1999) thereby aiding them in adjusting to life with disability.

Disability did not allay the men's belief that they deserved to be treated as men by society, and specifically by health care personnel. The young men desired respect and acceptance not only from health care providers, but from society as a whole. For these men, the health promotion experience involved a longing for validation. The men reported commonly looking to God to validate their bodies' existence and potential for health. Their lived experience of health promotion was reflected in the following themes: *Risking the Body to Preserve the Self, Accepting the Evolving Body, and Seeking the Body's Redemption*.

DISCUSSION

For the men in this study, health promotion was a process that began with the self. For them, health promotion was a journey to respecting, trusting, accepting, and understanding the self. The pursuit of health required the men to use their bodies as the means to establishing their authentic existence in the world. They yearned for confidence in their body's ability to support their desired reality. Health promotion was considerate of past and current circumstances and perspectives, while considering personal aspirations and goals.

According to Levinson (1986), "Early adulthood is the era in which we are most buffeted by our own passions and ambitions from within and by the demands of family, community, and society from without" (p. 5). Young adults are presented with significant life decisions shaped by one's interaction with the world around them. The process of maturing into and beyond young adulthood is disrupted and significantly impacted by disability (Dewis, 1989), thus the way in which the young adult male perceives his body has lifelong implications for his collective identity and how he experiences the world in which he lives (Dewis). Young adulthood is an integral period for shaping the long-term health promotion experiences of young adult African American men with impairment. The men of this study were challenged to balance personal and societal expectations with their subjective realities. Incongruent expectations and the perceived lack of attention to their health related needs made it difficult for the young men to pursue and maintain health.

Having a functional limitation and/or impairment that is not easily discernible to others does not make the transition to adulthood, nor the adjustment to life with impairment easy (Davis, 2005). The men in the current study reported experiencing the same shame and stigma that is common among persons with visible disabilities (Kelley-Moore, Schumacher, Kahana, & Kahana, 2006). The men reported that people, including health care providers, often thought they were faking their impairment because it was not overtly obvious to the onlooker. This "posture of doubt or suspicion" makes it impossible for health care personnel to truly appreciate the embodied experiences of persons with invisible impairments (Davis, p. 180); therefore, the men expressed difficulty in getting their health care needs met. According to Davis:

> The insistence upon the need to be able to verify the truth of an individual's claim to be suffering, in pain, or unable to function in the expected ways, and the assertion that it is only objective physical causes that have been given a medical imprimatur that can provide the needed verification, seem to presuppose the truth

> of claims that are, in fact, vulnerable to serious challenge. They seem to involve both the wholesale rejection of conceptual and clinical challenges to the adequacy of a purely physical, mechanistic understanding of health and the assumption that we now possess both a complete and an accurate understanding of how the body works and why the body fails (p. 182).

The patient-provider relationship is likely to be damaged by mutual mistrust, making it difficult for the provider to appreciate the contextualized existence of the people they are caring for.

Merleau-Ponty (1962) defined freedom as a form of consciousness that shapes how one responds and interacts with the world against a backdrop of what one perceives to be possible. The concept of freedom implies that there is not a "causal relationship...between the subject and his body, his world or society," (Merleau-Ponty, p. 504) yet how an individual finds meaning and responds in a situation is tempered by their culture and past experiences. Freedom breeds possibility dependent upon how the individual with impairment perceives themselves within a situation. In freedom:

> Consciousness can never objectify itself into invalid-consciousness or cripple-consciousness, and even if the old man complains of his age or the cripple of his deformity, they can do so only by comparing themselves with others, or seeing themselves through the eyes of others, that is, by taking a statistical and objective view of themselves, so that such complaints are never absolutely genuine: when he is back in the heart of his own consciousness, each one of us feels beyond his limitations and thereupon resigns himself to them...Hence we may speak disparagingly of our looks and still not want to change our face for another (Merleau-Ponty, p. 504-505).

For the young men in this study, embracing responsibility for the body and self lead to a sense of freedom (Merleau-Ponty, 1962). As was the case for a group of middle-aged and elderly women with disabilities (Harrison, Umberson, Lin, & Cheng, 2010), the men had to decide how they were going to perceive themselves and their potential for health. Like the women in the study conducted by Harrison and her colleagues, the men in the current study often felt a "sense of dissonance between their perception" (p. 824) of themselves and the way that others perceived them. They wanted their identities and

health potential to be based on more than the appearance of their bodies and its limitations.

Health-within-illness (Moch, 1998) emphasizes the opportunity to achieve health in the context of illness or impairment, thereby rendering the illness state a time of growth and transformation. For the men in this study, disability was a newfound opportunity to care for their bodies and pursue health. In disability, they had developed a renewed awareness of their bodies' limitations and needs. Although past experiences and interactions with health care personnel may have suggested that their bodies were not capable of achieving health, the men chose not to define their bodies' potential by imposed societal standards. Furthermore, the men felt that their bodies were worthy of health because it made their existence in the world possible. This notion differed from literature that sees eliminating the "illness" or disability as the goal of health promotion rather than considering disability an opportunity for growth and personal fulfillment (Moch, 1998; Patrick, 1997).

The way the men perceived their bodies was integral in shaping their reaction to living with impairment and pursuing health. Like the women in a study conducted by Nosek et al. (2004), the men in this study reported that the state of their bodies' influenced how they perceived the world and their capacity for health. Seeking health required that they accept their changed bodies, as well as the fluid nature of their existence (Husserl, 1999) thereby aiding them in adjusting to life with invisible impairment. In accepting who their changed bodies had allowed them to become in the world, the men embraced the evolvement of their embodied existence. This is consistent with the theoretical work of Stuifbergen (Stuifbergen, Becker, Blozis, & Beal, 2008; Stuifbergen, Harrison, Becker, & Carter, 2004; Stuifbergen & Rogers, 1997; Stuifbergen, Seraphine, & Roberts, 2000) who posited in her theoretical and empirical work that acceptance is necessary for the ultimate development of health promoting behaviors and a

higher quality of life among people with multiple sclerosis, fibromyalgia, and post-polio syndrome.

Personal narratives of the self are created as one interacts with the world around them (Nochi, 2000). "As part of this process of survival, the body tells stories" (Smith & Sparkes, 2008, p. 222). According to Smith & Sparkes, the impaired body is subject to a number of narratives. In their study of a young man paralyzed while playing rugby, Smith and Sparkes describe a phenomenon they refer to as "infiltrated consciousness" (p. 227) wherein the person with impairment incorporates into their embodied existence what society dictates to be an appropriate reality for their body. In doing so, the horizon of possibilities for their bodies is stifled. Smith (2013) describes an "emergent narrative" (p. 112) of health in his study of young adult men injured through sport. This "emergent narrative" of health directly opposes the "infiltrated consciousness" described by Smith and Sparkes in that it encourages an embodied narrative void of limitations or boundaries. The men who ascribed to Smith's "emergent narrative" considered the act of caring for the body and self as a springboard to self actualization and understanding of who they had the potential to become.

According to Benjamin Gregg (B. Gregg, personal communication, November 23, 2010), "Any observation of you will be less than what you are." Like the men in Smith's (2013) study, the men in the current study wanted to speak of embodied narratives based on their own perceptions, concerns, and values. They did not want to establish their bodies' potential or value based on the narratives of others, and they did not want to conform their identities solely to what society expected of a man with or without impairment. It was difficult for them to refute the imposed narratives of others due to the nature of their impairments. Their impairments were not easily justifiable; therefore, the validity of their embodied identity was often questioned. This is a common occurrence

among persons with invisible impairments (Boyles, Bailey, and Mossey, 2011; Butler, Derrett, & Calhoun, 2011; Lillrank, 2003; Mullins & Preyde, 2013; Stone, 2005).

"Disabled men are not generally located in our society's images of masculinity" (Shuttleworth, 2004, p. 166). According to Oksala (2006), "Being socialized to a culture and becoming a member of it means learning from others what counts as normal in the case of gender" (p. 235). Oksala goes on to assert that what is considered normal is not dictated by the physical body, but by the body's interface with culture and the environment. Masculinity ideals influenced how the men in this study experienced their bodies and the world surrounding their bodies on a day-to-day basis. According to Shuttleworth:

> The performance of gender occurs in sociocultural contexts (including imagined social interaction) in which people are invested in various ways in the outcomes of their encounters with others; during everyday interaction, interpersonal stakes involving identities, self-esteem, and quality of life are often very high (p. 169).

The men's belief in their manhood challenged the socially accepted ideals of masculinity related to physical prowess (Courtenay, 2000). The pain and weakness they experienced made it difficult for them to physically perform what society expected of them because of their seemingly "normal" outward appearance. The men's appearance of being vulnerable and dependent upon others could not be altered, at the same time, it was an affront to what they believed is commonly definitive of being a man in general and being an African American man more specifically (Courtenay); however, the men recognized that their construction of masculinity had to become flexible and dynamic in the context of impairment.

Similar to the men with severe arthritis in Gibb's study (2006) and the men in a study conducted by Coles et al. (2010), the young adult men in this study had to reconcile multiple identities (e. g. man with impairment, independent man) in order to surmise what manhood looked like for them. They had to modify the culturally normative ideals

of male behavior and revise what they considered masculine, in order to be able to consider themselves men. For example, similar to the men in a study conducted by Smith (2013), the young men considered caring for the self a sign of the initiative and assertiveness associated with masculinity; furthermore, it made the fulfillment of social roles possible; therefore, seeking health as a means of survival was indicative of their enduring manhood.

The young men were challenged to modify personal and social ideals of masculinity in order to renegotiate their interaction with the world around them. In the context of impairment, and even after recognizing the limitations of their bodies, the young men struggled to maintain an expected presentation of the self that reflected a hard-working, dependable, capable man. In their attempt to portray masculinity while pursuing health in the context of invisible impairment, the men chose to push their bodies even when it proved to be detrimental in the long run.

In their attempts to revise perceptions of their bodies and their environment, the men often put their bodies at risk in one form or another. In an effort to acquire or maintain an existence grounded in confidence and esteem, the men would ignore symptoms of injury or push their bodies beyond its limitations, often times resulting in further mental and physical injury. Harrison and Stuifbergen (2005) discovered similarities in their study of women with polio. Like the men in this study, the women who had aged with polio found themselves going beyond the limits of their bodies in an attempt to satisfy the needs of the self in regards to maintaining a sense of power over their circumstances. According to Charmaz (1994), the traditional ideals of masculinity that African American men tend to ascribe to (Courtenay, 1999) can form a "two-edged sword for men in chronic illness" (p. 283) by simultaneously encouraging self-esteem associated with risk taking and placing strict boundaries on what constitutes masculine behaviors. The men were constantly analyzing their gendered embodiment.

African American men are less likely to seek care from health care providers (Abernethy, Magat, Houston, Arnold, Bjorck, & Gorsuch, 2002; Addis & Mahalik, 2003; Millon-Underwood & Sanders, 1990). Acting in the context of a more traditional genre of masculinity, African American men tend to demonstrate their masculinity by avoiding health care and practicing risky behaviors (Courtenay, 2000). Among African American men, this prevalent viewpoint of masculinity emphasizes self-reliance, antagonism against "feminine" behaviors such as symptom acknowledgment, and encourages risky behaviors such as unprotected sex, to demonstrate maleness. The men in this study did not delineate between masculine or feminine health behaviors. For instance, the men did not state they behaved like women using language such as "I throw like a girl." Instead, they used gender neutral terminology. They shared experiences that mirrored a few of those proposed by Courtenay, specifically unprotected sex and the avoidance of healthcare. Please see Table 4 for a summary of how this study's findings attend to masculinity ideals.

	Findings
Disability	• Men with disabilities do not reflect masculine ideals in general, nor for African American men specifically[a] • The men's belief in their manhood challenged masculinity ideal related to physical prowess • Often pushed and damaged their bodies during attempts to maintain socially accepted ideals of masculinity
Defining Masculinity	• The men's definition of masculinity was constantly evolving in the context of impairment • Their defining attributes of masculinity consisted of reconciled notions of socially accepted and personal ideals.
Health Promoting Behaviors	• The men used gender neutral terminology to describe health promoting behaviors

Table 4 Addressing Masculinity

[a] Courtenay (1999)

For this group of young adult African American men, the health promotion experience meant putting the needs of the self before the needs of the body and then accepting and valuing the resulting condition of the body. Similar to a group of 11-20 year old adolescents (Patterson, 2010), the young men in this study came to accept the notion that living with permanent impairment would not, and could not, allow them to return to their former selves; however, unlike the participants in Patterson's study, the young men did not yearn to return to their former selves per se. Instead, they found themselves longing for a sense of normalcy based on their own values, expectations, and desires. In her study of young men with spinal cord injuries, Dewis (1989) discovered similar attempts to facilitate feelings of normality. The young men in Dewis' understood that they could never return to their previous level of functioning, but they could resume some sense of normalcy in their existence, perceptions, and interactions with others. I

posit that during their journey to achieving health, the young men in the current study were creating an alternative way of being or a new normal. While they did not consider themselves abnormal, they recognized that they were certainly different than before. Merleau-Ponty (1962) describes an insect with a bound leg as it adapts to the world around him:

> The insect simply continues to belong to the same world and moves in it with all its powers. The tied limb is not replaced by the free one, because it continues to count in the insect's scheme of things, and because the current of activity which flows towards the world still passes through it (p. 90).

The men discovered that adapting to the challenges of life was essentially the nature of health promotion. Their attempts at "preserving (the) self" (Charmaz, 1994, p. 278) encouraged them to become who they needed to be in order to survive and thrive. For them, health promotion reflected a renewed appreciation of their former, current, and future selves.

Seeking balance may have assisted the men in adjusting to living with invisible impairment, but it is important to be mindful of the difficulty they likely faced in pursuing health. Although aware of their bodies' needs, focusing on health promotion was not easy for the men while trying to fulfill social roles such as father, provider, and husband. For Merleau-Ponty (1962), the body enables a feeling of balanced existence while simultaneously preventing the prevalence of said feeling. Physical limitations made it difficult for the men to engage and navigate their world; however, those same limitations encouraged a renewed consciousness and appreciation of their bodies. During the "active adaptation" (Erickson, 1978, p. 28) to their changed existence in the world, the men considered their impairments both a detriment and an opportunity "which increased meaningfulness of life through connectedness or relatedness with the environment and/or awareness of self" (Moch, 1998, p. 305). Living with impairment had

made it difficult for them to achieve health, but also made health plausible and perhaps even more feasible than before they experienced impairment.

In her study using the concept of health-within-illness to explore the meaning of health among adults with disabilities, Lindsey (1996) used the themes of "Honoring the self" (p. 468) and "Acquiring a state of grace" (p. 469) to describe their experiences. In honoring the self, Lindsey found that participants developed a renewed desire to protect and cherish the self much like the participants in this study. As the men recognized and understood their body's potential, they were motivated to cherish God's gift of their body. In acquiring a state of grace, Lindsey found that participants developed an "awareness of their spirituality, with a sense of connectedness, wholeness, harmony and peacefulness" (p. 469). These findings are consistent with the men in this study who felt that seeking God's will in their lives was essential in that it validated their current existence in the world, as well as their right to experience health. Please see Table 5 for a summary of the ways in which the health promotion experience of this study's young men addressed the concept of health-within-illness (Moch).

Supports	**Deviates**
• Belief that health is dynamic and contextual • Belief that impairment spurred a renewed consciousness and awareness of self[a] • Considered disability an *opportunity* to pursue health[a] • Had a desire to relate to environment and health care personnel	• Relationship/Connectedness with the self (vs. others) and God was an integral aspect of health promotion • Accepting the evolving self was integral to pursuing health

Table 5 Addressing the Concept of Health-Within-Illness

[a]Moch (1998)

"From childhood to old age the learning to be human never ceases. Adulthood conceived in this way is not so much a state of attainment as a process of becoming" (Wei-ming, 1978, p. 113). In adulthood, pursuing an existence that reflects an inherent humanity is a sign of maturity (Wei-ming). In their quest for a more intimate relationship with God, they reported a desire for God to cultivate hopeful purpose and direction in their lives. Reconnecting with God served as a means for these young men to connect with their inherent humanity and become the men they believed God designed them to be. In addition, they developed a comprehensive understanding of themselves and began to honor the gift of their bodies and selves.

Traditionally, definitions of health promotion have tended to emphasize individual behaviors and responsibility (Patrick, 1997; Pender, Murdaugh, and Parsons, 2006). Some researchers (Harrison, 2006; Rimmer, 1999; Stuifbergen, 2006) believe that health promotion should be examined from a broader perspective considerate of societal influences. The men in this study contrived a description of health promotion consistent with the belief that personal, environmental, and social factors certainly influence health related perceptions and decisions; however, their health promotion experience was shaped primarily by the interplay of personal and societal perceptions of their bodies' potential and value. In conducting this study, the investigator was better able to understand the health promotion experience of a group of young adult African American men with invisible disability from their unique perspective. This understanding provided valuable insights into the rationales and philosophies that influenced their experience of health promotion.

CONCLUSIONS

The goal of this research was to explore how young adult African American men experienced health promotion in the context of invisible disability. During initial

discussions, it became apparent that prior to their injuries or impairments, the men had preconceived ideas regarding disability, health, and health promotion. The findings of this study suggest that those ideas were revised as a result of various experiences. The men were challenged to decide what health, health promotion, and masculinity meant for them in the context of impairment.

While the investigator found no literature exploring the lived experience of health promotion for young adult African American men with disabilities, she did discover a study conducted by Kim and Fox (2006) using a qualitative approach. In their study of the meaning of health among 18 persons with disabilities, they surmised that the meaning of health, like health promotion, is shaped by an individual's life experiences and interaction with their environment. The young African American men in this study of the lived experience of health promotion discovered that they were the only persons truly capable of experiencing their own bodies (Merleau-Ponty, 1962). I would posit that it was this realization that may have spurred a renewed responsibility for their bodies' well-being while living with impairment. The young men with invisible disabilities shared a variety of experiences that aided in the conceptualization of health promotion from their embodied perspective.

For these men, health promotion was a process that began with the self. It was considerate of past and current circumstances and perspectives. Health promotion was not something that health care providers could force or mandate because it began with a personal journey to the authentic self considerate of socially and personally imposed perceptions and ideals. This research was useful in its ability to illuminate the negotiation of identities that the young men used to achieve a sense of balance in their lives. This research is particularly useful in that it highlights the experience of men with disabilities who are doubly marginalized by society due to their race and impairment(s).

The men shared frustration about not getting the health care that they felt they needed. Health care providers are never able to realize what the total embodied experience of another human being is, but according to Husserl (1999), they are able to sensitize their consciousness to what it is for each individual. Health care providers must understand that health promotion is dynamic and it means different things for different people. The experience and meaning of health promotion can change based on the state of one's body, how one perceives their body, and the availability of resources that support functioning. As the body and self evolve, how health care providers approach patient interactions must evolve as well. In an effort to relate to young adult African American men with invisible disabilities, providers must learn to balance expectations with understanding and empathy, professionalism with compassion, giving and receiving advice, and teaching and learning. Like the men in this study, health care providersmmust let go of old ideals and values in order to facilitate health promotion among the people they care for. Smith and Sparkes assert that health care providers have to learn to seek and honor the narratives of young men with disabilities. "To deny their story is to deny the person telling this story which means that they cannot be cared for" (p. 231).

While the issue of race did come up occasionally when a few men expressed a desire to see more African American health care providers in the medical arena, the researcher deemed it important to mention the basis of their desire. The men did not necessarily feel that they would be better received or understood by an African American provider. They did report feeling more comfortable being cared for by someone who looked like them, but what they desired most was acceptance and respect. They wanted to trust the care that they received. Trust and acceptance from health care personnel seemed to be more salient factors to seeking health care than being of the same racial identity.

The stories shared by the young men of this study provide evidence of the need to examine health promotion in the context of young adulthood and impairment. Health

promotion behaviors and beliefs adopted in young adulthood, stand to have a significant impact on long-term health outcomes for young adult African American men with impairment.

LIMITATIONS

This study involved a small group of young adult African American men with invisible impairment living in Texas; therefore, the findings of this study are specific to their experience. It may be difficult to generalize the findings of this study to other populations or settings. The nature of this study's purpose, as well as its data collection and analysis processes, required the investigator to interpret the participant's experiences based upon their various forms of communication. It is possible that the interpretations of another investigator may yield different themes and subthemes; however, the investigator is hopeful that the careful and consistent use of hermeneutic phenomenology coupled with regular consultation with a qualitative expert, enhanced the trustworthiness of this research.

IMPLICATIONS FOR NURSING PRACTICE AND NURSING SCIENCE

Understanding the lived experience of health promotion has direct implications for nursing theory, practice, and research. Nurses may be better able to foster effective, long-term health promoting behaviors as they gain understanding of the health care needs, experiences, and desires of young adult African American men with invisible disability. This study raises awareness of the experience of a growing population of health care consumers, as well as provides insight into the context surrounding their health promotion experiences. The theoretical basis of nursing education, practice, and research will be strengthened by the addition of research findings that stand to improve the care that nurses provide.

Effective nursing care begins with sound knowledge and appreciation of an individual's assigned meaning and understanding of an experience. As the focus of health care for persons with disabilities continues to shift from disability prevention to health promotion (Rimmer, 1999), nurses have the opportunity to develop holistic, cost-effective, efficient models of effective health promotion (Patrick, 1997). Patrick asserts that effective health promotion interventions must allow for the influence of a person's social environment, economic resources, and constraints of the health care system.

For the men in this study, utilizing health care resources was considered to be potentially hazardous to their health. The men felt that they were risking their bodies by submitting them to the care of health care providers. This feeling lead to the desire to protect their bodies from provider mistakes and to protect the self by limiting exposure to harmful interactions. Nurses have the challenge and privilege of shaping the health experiences and trajectories of numerous individuals, families, and communities. This study will aid nurses in understanding the dynamic nature of the health promotion experience for young African American men with disabilities. Using findings from this and similar studies, nurses will be better able to find ways to support young men with disabilities in formulating positive perceptions of themselves and the world around them. Hopefully, nurses will come to consider disability an ideal opportunity for growth and health promotion, and be able to cultivate this belief among young adult African American men with disabilities, as well as society as a whole.

For the men in this study, health promotion began with a renewed consciousness of the self. The findings of this study suggest that nurses must expand their ideas regarding health and health promotion and understand that those concepts can mean different things for various groups of people. Among persons with disabilities, nurses need to encourage a renewed attentiveness to self and acceptance of the current body. Nurses are encouraged to remind young adult African American men of their enduring

manhood in context of disability. This may lead to a sense of orientation and comfort with the current embodied existence. Nurses are able to aid young men with disabilities in creating embodied narratives that foster health promoting attitudes and possibilities. According to Smith (2013):

> Health professionals can ambush people in contexts...by increasing the narrative resources people have access to, thereby expanding the number of narratives that are allowed to act—to do things for and in people. We can share and amplify stories that inspire people to create new sections in their inner library; stories individuals have not put themselves in a position to hear so that different ways of being a healthy male may be imagined (p. 117-118).

Nurses are challenged to change how we view health promotion in the context of disability so that we can encourage connectedness between the body, the self, and the world.

Nurses must learn to genuinely "see" an individual (Husserl, 1999) and focus their attention to the embodied experiences which help shape the personal definitions of health and health promotion. According to Husserl, everyone is embodied; therefore, we can expect to have the same experiences as one another. The ability to see a situation from another's perspective is essential for aiding nurses in learning how to facilitate an environment of acceptance and decreasing feelings of vulnerability. Spirituality was an integral aspect of the lived experience of health promotion for this study's young adult African American men. Perhaps, health promotion efforts targeting this group might consider and integrate spiritually based components that encourage self-respect and esteem.

In an attempt to expand the level of impact from this and similar studies, nurses must be challenged to broaden their scope of influence. By embracing our power to bring about social change, nurses can help rid the health care arena of care based on individual advantages, prejudice, and social biases. Through collaboration, nurses, along with other health researchers and providers, must put forth a collective effort to inform health policy

and improve the health of people with disabilities on a local, national, and an international level. A better understanding of the health promotion experience of young adult African American men with invisible disability may potentially improve the long term health outcomes of one of the most at risk groups of individuals.

FUTURE RESEARCH

This research provides evidence that health promoting interventions must consider the personal philosophies, values, and goals of young adult African American men with invisible impairment. While the health promotion experience of young adults of different racial and ethnic groups is likely to vary based on cultural and gender influences, additional research is needed to explore how and why differences occur. Further studies are needed to compare differences in the health promotion experiences of young adult African American men and men of other racial and cultural backgrounds in an effort to determine salient factors influencing health promoting behaviors. The author believes it is worthwhile to explore the intersection of masculinity, disability, and health promotion among men of various racial identities.

The men in this study spoke of the connection between their mental and physical well-being. For the men in this study, attention to the self was an important element of health promotion. Ruddick (2013) asserts, "The case for prevention and early intervention to support people's mental health has never been stronger" (p. 35). Focusing on their abilities rather than their limitations, aided the men in forming positive perceptions of their bodies. I recommend future research that explicitly explores the ways in which nurses can promote mental health among young men with disabilities "so that there is a greater emphasis on what patients can do, rather than on their disability or illness" (p. 38).

The men in this study experienced impairment at different points in their lives which has the potential to influence their health related choices (Harrison & Stuifbergen, 2005). Longitudinal research is needed to explore the dynamic process of health promotion and how it is altered depending on age at impairment onset and developmental period. While I hope that this research will help prevent further disability and impairment among African American men with disability, I recognize that there is a large population of men beyond young adulthood who could benefit from improved health related care and health promoting initiatives.

According to Stuifbergen (2006), there is a paucity of literature regarding the effectiveness of health promotion efforts targeting persons with disabilities. Additional research is needed to determine how nurses can best promote health among young adult African American men with disabilities. Perhaps health promotion theories that are individual focused, may prove beneficial in exploring the basis of health beliefs and attitudes among young adult African American men with invisible disabilities. I believe research is needed that explores effective strategies for health promotion targeting this group. For example, chronic cigarette and marijuana smoking were common among the men of this study. It is necessary to explore ways of encouraging smoking prevention and cessation among this group. It might also be beneficial to determine if participants began smoking before or after the onset of impairment. In addition, it would be useful to explore perceived barriers to seeking health care.

Additional research is recommended to explore differences in the health promotion experience of persons with invisible impairment and those with visible impairment. I believe it important to conduct research considerate of the evolving nature of individual and societal perceptions and expectations.

Appendix A: Sample Interview Questions**

1. Tell me about you and what it is like to live with the mobility challenges you have experienced.

2. We do different things to take care of our bodies. What kinds of things do you do on a daily basis to take of yours? Are there other things you have done, maybe not so regularly?

3. What was a typical day like before your impairment? What is a typical day like for you now?

4. Reflect for a moment on an experience when you've had to protect or take care of your body. What were the circumstances surrounding that experience? What was that experience like for you? Please share the impact that it has had on you.

5. When you're feeling bad (physically, mentally, or emotionally), what kinds of things do you do to feel better? What leads you to choose those things?

6. What does health mean to you? Would you describe yourself as a "healthy" person? Why or why not?

7. What are your concerns regarding your health? Have you ever expressed those concerns to or discussed them with a health care provider? What was done to address your concerns?

8. If you had to give doctors and nurses advice on how to help you take care of your health what would you tell them and why?

9. Tell me about the challenge(s) you have had in taking care of your health.

**Probes will be used to encourage the participant to continue talking and to explore areas of interest related to health promotion in the context of mobility impairment. These include nodding, restating a word they used, asking them to go on, and reiterating my interest in the topic.

Appendix B: Demographic Information

1. What is your age? _____

2. What is your highest level of education? _____

a. Elementary

b. Junior high school (middle school)

c. High School

d. Some college

e. Associate's degree

f. Bachelor's degree

g. Graduate degree

3. Do you currently have paid employment? _____

4. Are you currently seeking paid employment? _____

    a. If yes, for what length of time? _____

5. From the list below, what is your current marital status?

    a. Married

        i. How long? ____

    b. Divorced

        i. How long? ____

    c. Live with significant other

i. How long? _____

d. Widowed

i. How long? _____

e. Separated

i. How long? _____

f. Never married

6. From the list below, what type of health insurance do you have?

a. No insurance

b. Private pay insurance

c. Private pay insurance through my employer

d. Medicare

e. Medicaid

f. MAP (Medical Access Program)

g. VA

h. I am not sure

7. What is your weight to the nearest pound? _____

8. What is your height? _____

9. From the list below, in what type of residence do you live?
a. I own my own home.

b. I own my own condominium.

c. I rent a home.

d. I rent an apartment or duplex.

e. I live with family in their home.

f. I live with family in their apartment or duplex.

g. I am currently without a place to live.

h. Other _____

10. What best describes your living arrangement?
    a. I rent.
    b. I own my residence.
    c. I live in government assisted housing.
    d. My family helps to pay my living expenses.
    e. Other _____

11. In what county in Texas are you currently living?

12. How many people currently live with you?

13. From the list below, what is your approximate annual income?
    a. less than 10,000
    b. 10,000 – 19,999
    c. 20,000 – 29,999
    d. 30,000 – 39,999
    e. 40,000 – 49,999
    f. 50,000 – 59,999
    g. 60,000 – 69,999
    h. 70,000 or more

14. Do you have children? _____
    a. If yes, how many children do you have? _____
    b. If yes, how old are your children? _____

15. At what age did you lose the ability to do many of the things that you want or would like to do? _____

16. Do you have a sports related injury?_____

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This dissertation was typed entirely by the author.